S. Hrg. 105–262

MEDICAID MANAGED CARE: THE ELDERLY AND OTHERS WITH SPECIAL NEEDS

FORUMS

BEFORE THE

SPECIAL COMMITTEE ON AGING UNITED STATES SENATE

ONE HUNDRED FIFTH CONGRESS

FIRST SESSION

WASHINGTON, DC

PEOPLE WITH SPECIAL NEEDS, JUNE 24, 1997
THE STATE OF THE INDUSTRY, JULY 8, 1997
QUALITY AND OUTCOME MEASURES, JULY 15, 1997
THE STATE OF THE STATES, JULY 22, 1997

Serial No. 105–9

Printed for the use of the Special Committee on Aging

U.S. GOVERNMENT PRINTING OFFICE
44–098 WASHINGTON : 1997

For sale by the U.S. Government Printing Office
Superintendent of Documents, Congressional Sales Office, Washington, DC 20402
ISBN 0-16-055952-9

SPECIAL COMMITTEE ON AGING

CHARLES E. GRASSLEY, Iowa, *Chairman*

JAMES M. JEFFORDS, Vermont
LARRY CRAIG, Idaho
CONRAD BURNS, Montana
RICHARD SHELBY, Alabama
RICK SANTORUM, Pennsylvania
JOHN WARNER, Virginia
CHUCK HAGEL, Nebraska
SUSAN COLLINS, Maine
MIKE ENZI, Wyoming

JOHN B. BREAUX, Louisiana
JOHN GLENN, Ohio
HARRY REID, Nevada
HERB KOHL, Wisconsin
RUSSELL D. FEINGOLD, Wisconsin
CAROL MOSELEY-BRAUN, Illinois
RON WYDEN, Oregon
JACK REED, Rhode Island

THEODORE L. TOTMAN, *Staff Director*
BRUCE D. LESLEY, *Minority Staff Director*

CONTENTS

PEOPLE WITH SPECIAL NEEDS, JUNE 24, 1997

LIST OF WITNESSES

THE STATE OF THE INDUSTRY, JULY 8, 1997

LIST OF WITNESSES

QUALITY AND OUTCOME MEASURES, JULY 15, 1997

LIST OF WITNESSES

THE STATE OF THE STATES, JULY 22, 1997

LIST OF WITNESSES

APPENDIX

ADDITIONAL STATEMENTS AND MISCELLANEOUS MATERIAL SUBMITTED FOR HEARING RECORD

PEOPLE WITH SPECIAL NEEDS

TUESDAY, JUNE 24, 1997

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The forum met, pursuant to notice, at 9:30 a.m., in the Dirksen Senate Office Building. Ms. Susan Christensen, Public Policy Fellow, presiding.

OPENING STATEMENT OF SENATOR CHARLES GRASSLEY, CHAIRMAN

Each year, States have enrolled increasing numbers of Medicaid beneficiaries into mandatory managed care plans. For many of these beneficiaries, Medicaid managed care provides services that were otherwise unavailable. Yet many beneficiaries currently enrolled in managed care have experienced serious difficulties in accessing appropriate health care services. As States begin to consider enrolling additional groups of Medicaid beneficiaries into managed care plans, namely elderly and persons with special needs, it is essential that we take a close look at the kind of care that these populations require, and whether managed care is ready and able to provide these services.

In order to examine the impact of mandated Medicaid managed care on the elderly and others with special needs, the Aging Committee planned this series of forums which takes a critical, yet balanced, look at the changes brought about by the use of managed care in Medicaid programs.

A careful assessment should be made of the structural features of Medicaid managed care plans that can affect the delivery of care to persons who are elderly or have special needs. These forums are an important source of information that I hope will shed light on the challenges that both beneficiaries and States face as mandated managed care becomes a reality for many people with chronic conditions.

It is clear that States will have to resolve difficult issues when they develop managed care programs that enroll people with chronic conditions. It is especially important that States make informed decisions when selecting plans to serve vulnerable populations. At this time there is considerable concern that most managed care plans are not yet prepared to effectively serve special needs populations. This does not mean that persons with special needs will never fare well in managed care. In fact, it is clear that there are managed care plans that are doing an excellent job. However, it is also apparent that structuring a plan that serves this population is very different from creating a plan for the younger, healthier population that managed care has traditionally served.

Through these forums the Committee will examine the current state of the managed care industry. We will learn about both the successes and the failures and discover where more work needs to be done. Finally, I hope these forums will provide leadership for States and advocates to work together to develop managed care programs which will provide quality care for all populations.

OPENING STATEMENT OF MS. SUSAN CHRISTENSEN

Ms. CHRISTENSEN. I am Susan Christensen, and I am a Fellow with the Aging Committee, with Senator Grassley's staff. Also here we have, with Senator Grassley's staff Hope Hegstrom, and Ken Cohen is here from Senator Breaux's staff on the Committee.

This is the first in a series of four forums on managed care. Individually, several Aging Committee staff have been following the research and changes in managed care for some time, but our interest became acute when we conducted a hearing recently on the special needs of people with health conditions who were eligible for Medicare and Medicaid.

There are some significant issues that need to be resolved when we talk about managed care for people with special needs, and we have divided these issues roughly into four main themes, which are the topics of our four forums. We won't cover all the issues, but we hope to give you a sense of the amount of work that has been done and that still needs to be done; and we will have the generous support of the GAO staff throughout all this, which we appreciate very much.

Today, we will start with the basics. Our panelists are here to give you a picture of what we mean when we say a "person with special needs." These are citizens who don't just need more care, they need care delivered in certain ways for it to be effective. Within the category of special needs, there are broad variations.

Some information that you will hear today is very basic, but each of our panelists is an expert on the health care system as it applies to the populations that they represent. So I hope you will take the opportunity to ask them any questions that might come to mind as you hear them speak. We have some forms that you can use; jot your questions down as you listen, and you can ask them at the end.

We plan to talk for about an hour, and we'll have half an hour after that for questions and interactions. We are making a record of today, and we'll make a record of each of our forums which will be available from the committee later when we finish up.

Future forums will build on this one. The next one is July 8 and will look at the existing managed care industry and current approaches to meeting the needs of individuals that we'll hear about today.

After that, on July 15, we will focus specifically on how plans measure quality for a population that is so statistically small.

On July 22, we'll look at the State of the States to contract for managed care plans that might be necessary for special needs.

Again, I want to thank LaVita Westbrook and Meredith Levenson for their assistance. I appreciate it.

Our panelists today—and I'm not even sure that they have all met each other; we are being a little less formal than in a hearing—in not any particular order, I will introduce our panelists.

Our first is Al Guida, who is vice president of the National Mental Health Association, where he coordinates education and State-level advocacy efforts of the organization's field network encompassing 326 affiliates in 43 States. He spent much of the last 10 years working on children's policy issues at the Federal and State level.

I am also pleased to introduce Tony Young, who is a policy associate in the Governmental Activities Department of United Cerebral Palsy Associations. He is an advisor to several national projects.

Kathy McGinley is the assistant director at The Arc, formerly the Association for Retarded Citizens, of the United States. She coordinates efforts of the Health and Housing Task Forces of the Consortium for Citizens with Disabilities. She helped to develop the CCD Health Task Forces's "Principles for Health Care Reform from a Disability Perspective."

Nancy Leonard is a care manager at Connecticut Community Care, an independent care management organization currently serving over 3,500 older adults statewide in Connecticut. She has 11 years of care management experience with the frail elderly in the community, and she is here on behalf of the Alzheimer's Association in Connecticut.

Donald Minor comes from Tennessee, where he works as a client advocate for Caremark. He is a person living with hemophilia who was diagnosed with HIV in 1985. He has been a health care advocate for more than 10 years and has been a recipient of TennCare since its inception in 1994. He is here today representing the National Association of People with AIDS.

I think we'll go ahead and let you folks get started. We'll just go down the table, hear the presentations, and save questions until the end.

Tony.

STATEMENT OF TONY YOUNG, POLICY ASSOCIATE, UNITED CEREBRAL PALSY ASSOCIATIONS, WASHINGTON, DC

Mr. YOUNG. Good morning. Thank you for this opportunity to present you with some profiles of individuals with physical disabilities and their need for health care and long-term services. I have attempted to select profiles of individuals of varying ages, conditions and needs for services. While they do not cover the full gamut of circumstances and needs, they are nonetheless representative of many people with disabilities who are facing the uncertain prospect of receiving their health care and long-term services from managed care providers.

I have four profiles to share with you this morning, and I will try to get through as many of them as time will allow.

Our first profile is of a 12-year-old male with severe cerebral palsy, along with mild cognitive impairment and a seizure disorder. He is actually here with us this morning, but managed to escape through the doors when somebody opened them. Hopefully, he will be back in a few minutes, and you will be able to see this young man.

He speaks only with great difficulty and cannot perform activities of daily living, or ADLs, or instrumental activities of daily living, or IADLs, without assistance. ADLs include bathing, dressing, transferring, eating, and toileting. IADLs cover managing money, taking medications, doing light housework, preparing meals, and moving about outside the home.

This individual uses augmentative communication aids, such as a Liberator, to communicate with family, friends and others. A Liberator is a device that enables a person with a speech limitation to communicate by typing words and phrases onto a keyboard and having the device speak those words in a synthetic voice.

He requires personal assistance to perform his ADLs and IADLs. We define "personal assistance" as one or more individuals or devices that assist a person with a disability to perform activities that they would otherwise perform for themselves if they did not have a disability.

He requires assistive technology in the form of a motorized wheelchair for mobility. He needs developmental and maintenance physical, occupational, and speech therapy in order to improve his functional abilities. He depends on prescription medication to control his seizures.

His family requires respite care services and family support counseling services and would greatly benefit if there were better, or in fact any, continuity of care personnel. Currently, the turnover rate among his PAS providers is so high it is impossible to maintain a uniform quality of service. He needs periodic examinations by specialists in physical medicine, dentistry, neurology, pediatrics, orthopedic surgery, and routine health screening who are knowledgeable of people with disabilities. Service coordination would improve the collective impact of his health care and related services.

Our second profile is of a 41-year-old woman with spina bifida and multiple secondary disabilities which have resulted in a double leg amputation. She also has chronic bladder and kidney problems, and a rare blood clotting disorder. She has a history of problems with decubitus ulcers, which are commonly known as pressure sores. She needs help in performing some instrumental activities of daily living. She can ambulate using artificial legs, but only with great difficulty.

This individual needs the services of several specialists, including a urologist, a neurologist, an orthopedist, an internist, a hematologist and a gastroenterologist. My word processing software hated "gastroenterologists." She also requires periodic urological lab tests, assistive technology for prosthetics and a manual wheelchair, and routine health screening.

Service coordination is essential for this person due to the complex interactions of her disability, spina bifida, and the chronic health conditions that are not related to her disability but that greatly impact her health.

A third profile is a 45-year-old male with quadriplegia who has severely limited wheelchair sitting time as a result of a history of decubitus ulcers. He has chronic muscle spasticity and urinary tract infections. He cannot perform activities of daily living or instrumental activities of daily living with out assistance. One kidney ceased functioning due to a series of UTIs several years ago and was surgically removed.

This person needs prescription medications to manage spasticity and the urinary tract infections. This must be supported by ongoing lab tests to identify the urinary tract infection and to monitor kidney and liver function to detect drug-related side effects such as liver damage. He needs to be regularly evaluated by a physical medicine specialist and a urology specialist.

His general health care should be monitored by a psychiatrist or other physician knowledgeable about the unique impacts of spinal cord injury upon major body systems, specially the urological system. He requires ongoing physical therapy to maintain functional abilities and personal assistance with both ADLs and IADLs. His assistive technology needs include a powered wheelchair, various seat cushioning and positioning systems, and arm splints. Routine health screening and service coordination is required.

Our fourth profile is a 29-year-old woman with cerebral palsy who walks with a limp but without any mobility assistance. She has no speech difficulties. She wants to have children when the time is right. She was recently rejected by a managed care provider due to her cerebral palsy. As she ages, the effort that it takes for her to walk will age her joints and tendons more rapidly than normally. Eventually, she will require some assistive technology with mobility, such as a scooter, causing a reduction in the amount of exercise she gets. This will require a modification in her diet, her physical therapy, and her exercise regime.

This person requires routine health screening and ongoing physical therapy to maintain her current good health. When she is ready to have children, she will need obstetric and gynecological services from a specialist knowledgeable about disability. As she ages, she will require an orthopedist or physical medicine specialist to assist her in determining which mobility aids he should use to balance the competing needs for mobility and exercise.

In summary, although it is difficult to draw conclusions from only four profiles of individuals with disabilities, there are several overarching themes that can be identified.

The first and most important theme is the need for access to a variety of specialists, especially those knowledgeable about disability. These specialists may or may not be most effective playing the role of primary care physician, depending on the unique needs of each individual.

The second theme is the need for home and community-based long-term services and assistive technology. These essential supports enable individuals with disabilities to access health care, to work, to attend school, and to recreate. They are critical for the prevention of secondary disabilities, because they enable people with disabilities to avoid behaviors that trigger secondary conditions. The classic example is spinal cord-injured persons who restrict drinking fluids because they have no assistance in using the bathroom, which leads to urinary tract infections.

Prescription medications assist people in managing the myriad conditions that often accompany disability. They too can prevent or delay the onset of secondary disabilities and debilitating conditions that can transmute into expensive acute care episodes.

Service coordination is needed to afford continuity among the many specialists and related service personnel, including long-term services, assistive technology and social services, that people with disabilities use. Appropriate application of coordination, as opposed to case management, of health and related services can both raise the quality of services delivered and reduce the cost of these services.

One often overlooked theme is that most individuals with disabilities are quite healthy. Routine health screenings to maintain this good health are vital for the prevention of secondary disabilities as well as the prevention of other common ailments affecting the general population.

In my written statement, I have attached a list of important principles for your consideration when designing managed care programs intended to serve individuals with disabilities. I want to thank you for your attention this morning and, after everybody else has spoken, I would be glad to answer any questions you might have.

Ms. CHRISTENSEN. Thank you very much.

[The prepared statement of Tony Young follows:]

BRIEFING FOR CONGRESSIONAL STAFF
ON NEEDS OF
PERSONS WITH PHYSICAL DISABILITIES
- IN MANAGED CARE

JUNE 24, 1997

Tony Young
Policy Associate
United Cerebral Palsy Associations
1660 L Street, NW Suite 700
Washington, DC 20036
Tel: 202/973-7112
e-mail: tyoung@paltech.com

BRIEFING FOR CONGRESSIONAL STAFF ON NEEDS OF PERSONS WITH PHYSICAL DISABILITIES IN MANAGED CARE

Thank you for this opportunity to present you with some profiles of individuals with physical disabilities and their need for health care and long-term services. I have attempted to select profiles of individuals of varying ages, conditions, and needs for services. While they do not cover the full gamut of circumstances and needs, they are nonetheless representative of many people with disabilities who are facing the uncertain prospect of receiving their health and long-term services from managed care providers. I have four profiles to share with you this morning; we will try to get through as many as time will allow.

Profiles of Health Care Needs of Individuals with Physical Disabilities

Profile 1: A 12 year old male with severe Cerebral Palsy, coincident with mild cognitive impairment and a seizure disorder. He speaks only with great difficulty, and cannot perform Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs) without assistance. ADLs include bathing, dressing, transferring, eating, and toileting. IADLs cover managing money, taking medications, doing light housework, communicating over the telephone, shopping for groceries or clothes, preparing meals, and moving about outside the home.

Needs: This individual uses augmentative communications aides, such as a Liberator, to communicate with family, friends, and others. A Liberator is a device that enables a person with a speech limitation to communicate by typing words and phrases onto a key board and having the device speak those words in a synthetic voice. He requires personal assistance to perform ADLs and IADLs. Personal assistance is defined as one or more individuals or devices that assist a person with a disability to perform activities that they would otherwise perform for themselves if they didn't have a disability. He requires assistive technology in the form of a motorized wheelchair for mobility. He needs developmental and maintenance physical, occupational, and speech therapy in order to improve his functional abilities. He depends on prescription medication to control seizures. His family requires respite care services and family support counseling services, and would greatly benefit if there were better (or any) continuity of his care personnel; currently the turnover rate among his PAS providers is so high it is impossible to maintain a uniform quality of service. He needs periodic examinations by specialists in physical medicine, dentistry, neurology, pediatrics, orthopedic surgery, and routine health screening who are knowledgeable of disability. Service coordination would improve the collective impact of his health care and related services.

Profile 2: A 41 year old woman with *Spina Bifida* and multiple secondary disabilities resulting in double leg amputation. She also has chronic bladder and kidney problems; a rare blood disorder; and a clotting disorder. She has a history of problems with decubitus ulcers, which are commonly known as pressure sores. She needs help in performing some Instrumental Activities of Daily Living (IADLs). She can ambulate using artificial legs, but only with great difficulty.

Needs: This individual needs the services of several specialists, including a urologist, neurologist, orthopedist, internist, hematologist, and a gastroenterologist. She also requires periodic urological lab tests, assistive technology for prosthetics and a manual wheelchair, and routine health screening. Service coordination is essential for this person due to the complex interactions of her disability, *Spina Bifida*, and the chronic health conditions that are not related to her disability but that greatly impact her health.

Profile 3: This person is a 45 year old male with quadriplegia who has severely limited wheelchair sitting time as a result of a history of decubitus ulcers. He has chronic muscle spacisity and urinary tract infections (UTI). He cannot perform Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs) without assistance. One kidney ceased functioning due to a series of UTIs several years ago and was surgically removed.

Needs: This person needs prescription medications to manage spacisity and UTI. This must be supported by ongoing lab tests to identify UTI and to monitor kidney and liver function to detect drug related side effects such as liver damage. He needs to be regularly evaluated by a physical medicine specialist and a urology specialist. His general health care should be monitored by an internist or other physician knowledgeable about the unique impacts of spinal cord injury upon major body systems, especially the urological system. He requires ongoing physical therapy to maintain functional abilities and personal assistance with both ADLs and IADLs. His assistive technology needs include a powered wheelchair; various seat cushioning and positioning systems; and arm splints. Routine health screening and service coordination is required.

Profile 4: This individual is a 29 year old woman with Cerebral Palsy who walks with a limp but without mobility assistance. She has no speech difficulties. She wants to have children when the time is right. She was recently rejected by a managed care provider due to Cerebral Palsy. As she ages, the effort that it takes for her to walk will age her joints and tendons more rapidly than normal. Eventually she will require some assistive technology with mobility, such as a scooter, causing a reduction in the amount of exercise she gets. This will require a modification in her diet, her physical therapy, and her exercise regime.

Needs: This person requires routine health screening and on-going physical therapy to maintain her good health. When she is ready to have children, she will need obstetric and gynecological services from a specialist knowledgeable about disability. As she ages, she will require an orthopedic or physical medicine specialist to assist her in determining which mobility aides she should use to balance the competing needs for mobility and exercise.

Summary Needs: Although it is difficult to draw general conclusions from only four profiles of individuals with disabilities, there are several overarching themes that can be identified from these people.

- The first and most important theme is their need for **access to a variety of specialists,** especially those knowledgeable about disability. These specialists may or may not be most effective playing the role of primary care physician, depending upon the unique needs of each individual.

- The second theme is the need for **home and community-based long-term services and assistive technology**. These essential supports enable individuals with disabilities to access health care, to work, to attend school, and to recreate. They are critical for the prevention of secondary disabilities, as they enable people with disabilities to avoid behaviors that trigger secondary conditions. The classic example is spinal cord injured persons who restrict drinking fluids because they have no assistance in using the bathroom, which leads to a urinary tract infection.

- **Prescription medications** assist people in managing the myriad conditions that often accompany disability. They too can prevent or delay the onset of secondary disabilities and debilitating conditions that can transmute into expensive acute care episodes.

- **Service coordination** is needed to afford continuity among the many specialists and related service personnel (long-term, assistive technology, and social services). Appropriate application of coordination, as opposed to case management, of health and related services can both raise the quality of services delivered and reduce the cost of these services.

- One often overlooked theme is that most individuals with disabilities are quite healthy. **Routine health screenings** to maintain this good health are vital for the prevention of secondary disabilities as well as the prevention of other common ailments affecting the general population.

I have attached a list of important principles for your consideration when designing managed care programs intended to serve individuals with disabilities. Thank you for the opportunity to share this information with you. I would be happy to answer any questions you might have.

CHARLES E. GRASSLEY, IOWA, CHAIRMAN

JAMES M. JEFFORDS, VERMONT
LARRY E. CRAIG, IDAHO
CONRAD BURNS, MONTANA
RICHARD C. SHELBY, ALABAMA
RICK SANTORUM, PENNSYLVANIA
JOHN W. WARNER, VIRGINIA
CHUCK HAGEL, NEBRASKA
SUSAN COLLINS, MAINE
MIKE ENZI, WYOMING

JOHN B. BREAUX, LOUISIANA
JOHN GLENN, OHIO
HARRY REID, NEVADA
HERB KOHL, WISCONSIN
RUSSELL D. FEINGOLD, WISCONSIN
CAROL MOSELEY-BRAUN, ILLINOIS
RON WYDEN, OREGON
JACK REED, RHODE ISLAND

United States Senate
SPECIAL COMMITTEE ON AGING
WASHINGTON, DC 20510-6400

The Consortium for Citizens with Disabilities
Health Task Force

Principles for Managed Care for People With Disabilities

July, 1996

The CCD Health Task Force "Principles for Health Care Reform from a Disability Perspective" have been used since their development in 1991 to assess the ability of health care reform measures to meet the needs of people with disabilities. The CCD asserts that any effort to reform the nation's health care system must be built on five basic principles: non-discrimination, comprehensiveness, appropriateness/choice, equity, and efficiency.

This means that:

- both the public and private health care systems must not discriminate against people with disabilities;
- these systems must make a full range of health and health related services and supports available to people with disabilities in an efficient manner based on their individual needs and choices and
- people with disabilities must not be burdened with inequitable and disproportionate costs which limit their access to services

Policy makers at both the national and state levels must recognize that there are at least 43 million people with disabilities in the United States, as well as a large number of others with special health care needs. This includes individuals of all ages with physical and mental impairments, conditions, or disorders that are severe, acute, or chronic which limit or impede their ability to function. Therefore, reform efforts must take into consideration the needs of people with disabilities.

Currently, the role of managed care occupies center stage in the health care debate. Managed care is viewed by many as a means to control health care costs while at the same time promoting good health. However, this is not the view of the disability community. Reports from consumers with disabilities indicate that access to necessary services is either denied or severely limited by managed care organizations because of a lack of understanding of the needs of individuals with disabilities.

Building on its earlier work, the CCD Health Task Force has developed the following managed care principles to help consumers and advocates evaluate current and emerging managed care

CHARLES E. GRASSLEY, IOWA, CHAIRMAN

JAMES M. JEFFORDS, VERMONT
LARRY E. CRAIG, IDAHO
CONRAD BURNS, MONTANA
RICHARD C. SHELBY, ALABAMA
RICK SANTORUM, PENNSYLVANIA
JOHN W. WARNER, VIRGINIA
CHUCK HAGEL, NEBRASKA
SUSAN COLLINS, MAINE
MIKE ENZI, WYOMING

JOHN B. BREAUX, LOUISIANA
JOHN GLENN, OHIO
HARRY REID, NEVADA
HERB KOHL, WISCONSIN
RUSSELL D. FEINGOLD, WISCONSIN
CAROL MOSELEY BRAUN, ILLINOIS
RON WYDEN, OREGON

United States Senate
SPECIAL COMMITTEE ON AGING
WASHINGTON, DC 20510-6400

proposals, practices, standards and guidelines and ensure their appropriate application to people with disabilities. This is a set of guiding principles. It is not a "cook book" for the perfect managed care system. These principles should be viewed only as a starting place by advocates who are working to ensure that managed care systems meet the varied needs of children and adults with disabilities and their families.

> *Issues in managed care concerning long term services and supports for people with disabilities are not expressly addressed in this document. Other CCD materials address these issues. However, the CCD wants to stress that if a managed care entity is responsible for any long term services and supports, these must be provided in accordance with best practices and emphasize community-based, consumer directed services. Long term services must not become overly medicalized because a health care entity is responsible for payment. Consumers of long term services must be given choices and a full range of quality assurance measures must be available based on individual needs and personal preferences about types, methods, providers, and sites of services.*

Principles For Managed Care For People With Disabilities

The CCD believes that if managed care systems/plans are to meet the needs of people with disabilities, they must embody the following principles.

Consumer Participation

Managed care systems/plans must ensure that all key stakeholders, including individuals with disabilities, family members, support agencies, providers, advocates, and others are enlisted in designing, implementing, and overseeing the operation of both public and private managed care systems and plans.

Managed care systems/plans must not encourage placement in institutions but, instead, encourage the provision of services that support people to live as independently as possible and to participate in the every day life of the community.

Consumer Choice

Managed care systems/plans must expand, not diminish, opportunities for people with disabilities and their families to choose services and supports that will improve the quality of their lives.

Managed care systems/plans must be structured in a manner that decentralizes decision making and promotes innovation in providing appropriate services and supports to people with disabilities.

Managed care systems/plans must provide enrollees with a choice of plans or offer an affordable point of service option. However, the availability of a point of service option must not mean that managed care plans do not have the responsibility to provide appropriate care or pay for an out-of-network referral if the managed care plan cannot provide a service.

Appropriate Definition of Medical Necessity

For individuals with disabilities, the term "medical necessity" must be defined in the broadest manner possible to ensure access to all appropriate services and supports that can enable a person with a disability to function in the community as independently as possible.

Equitable Financing Mechanisms

Any financing mechanism that may directly or indirectly constrain access to appropriate services must be prohibited.

Managed care systems/plans must not include financial incentive procedures that directly or indirectly restrict access or deny adequate and appropriate services. Systems/plans that contain incentives for individual providers regarding utilization of services must not link financial rewards/penalties with individual treatment decisions.

Managed care systems/plans must have "stop-loss" provisions or limits to risk that are mutually agreed upon by providers and plan sponsors when provider groups (particularly small groups) assume financial risk for the cost of specialty care, ancillary services, and/or hospital care. Additional amounts of provider time or effort required by people with disabilities or chronic illness must be compensated commensurate with the additional effort required, either as a component in the capitation agreement or through some mutually agreeable financial arrangement.

Managed care systems/plans must collect utilization data over periods of time sufficient to identify patterns of risk. Risk sharing arrangements across a group of providers must also be based on the performance of the provider group over periods of time.

Consumers Benefit from Cost Savings

Managed care systems/plans must be designed to ensure that cost savings realized through the more efficient administration of services are invested primarily in providing services and supports and reducing waiting lists for eligible beneficiaries.

Appropriate Services and Benefits Available

Managed care systems/plans must offer a comprehensive benefits package that meets the needs of

people with disabilities and special health care needs. This includes such basic benefits as prescription drugs, preventive services, rehabilitation services, durable medical equipment, orthotics and prosthetics, and mental health services
Managed care systems/plans must offer all necessary benefits, services, and supports across multiple settings, such as home, school, work. There must be no arbitrary limitations on service settings.

Managed care systems/plans must not include disincentives, financial or otherwise, to the provision of services in home and community-based settings.

Managed care systems/plans must be structured to ensure continued, appropriate access to health and health related services.

Services should be provided not only to treat acute and chronic conditions but also to promote and maintain health and optimum functioning and prevent deterioration and secondary disabilities.

Managed care systems/plans must have specific limits on waiting times for first appointments and for specialty referrals. To assure geographic accessibility of services, there must also be established standards for travel times and distances to both primary and specialized services.

Access to Specialty Services

Managed care systems/plans must provide for access to and the effective coordination of specialized services with other systems/supports on which people with disabilities rely.
Managed care systems/plans must offer people with disabilities and special health care needs the option of having a specialist as their "gatekeeper" in the system/plan. This specialist would provide both necessary specialized services -- at the specialized rate -- and primary care services -- at the lower primary care reimbursement rate.

Strong Quality Assurance Measures

Managed care systems/plans must comply with the protections offered by Section 504 of the Rehabilitation Act of 1973, as amended, the Americans with Disabilities Act, and other civil rights statutes.

Managed care systems/plans must provide participants with clear information on policies, procedures, grievance mechanisms, and appeals and must ensure consumer participation in the establishment of such procedures.

Managed care systems/plans must provide access to independent organizations that provide ombudsman and rights protection services.

Managed care systems/plans must have in place a mechanism for responding to adverse utilization review by including appropriate grievance and appeals mechanisms.

Managed care systems/plans must include mechanisms for avoiding discrimination in the provision of services. This includes the prohibition of arbitrary limits through reasonable accommodations in such areas as benefits, location of services, length of treatment, and geographical location.

Managed care systems should be required to provide health care services in accordance with nationally accepted prevention and treatment protocols, e.g. protocols for prenatal care, well-baby care, and childhood immunization schedules, or current best-practices.

Managed care systems/plans must communicate to enrollees and prospective enrollees which services are covered and which are excluded in a consistent format that is clear and easily understood. Included must be information on co-payments, deductibles, the existence of any utilization review requirements, as well as any financial incentives that restrict or require the use of specific providers, facilities, services, or products.

Managed care systems/plans that utilize provider risk sharing arrangements or other incentives related to utilization of services must have established mechanisms in place for monitoring quality of care.

Managed care systems must include the option to disenroll for those participants who are not receiving adequate and timely services.

Managed care systems/plans must be required to collect and report a uniform set of data that allows public officials and consumers to evaluate and compare performance, including longitudinal data to measure outcomes for people with disabilities. Community agencies and consumers must be involved in design of and ongoing participants in quality assurance systems which focus on appropriate outcomes for the individual.

Managed care systems must have strict quality assurance provisions that require internal and external review mechanisms by independent assessors and the results of these reviews should be available to consumers to assist them in choosing a managed care plan. Individually focused outcome reviews should be a key component of this process.

Consumer Education

In order to avoid marketing abuses by managed care plans, states must be required to prohibit direct enrollment by plans and instead set up an independent enrollment and counseling process which permits enrollees -- in the public and private markets -- to explore options in choosing among plans. All such efforts must be designed to respond in a non-discriminatory manner to the varying abilities and needs of people with disabilities.

Managed care systems/plans must disclose in a clear and easily understood manner to enrollees and prospective enrollees the plan's policy with regard to withholds, privileges, denials of payment, and any other mechanism with a utilization/financial incentive link.

Managed care systems/plans must establish a means by which consumers and payers can accurately evaluate and effectively choose plans on the basis of measured results.

Al.

STATEMENT OF ALFONSO V. GUIDA, JR., VICE PRESIDENT, NATIONAL MENTAL HEALTH ASSOCIATION, ALEXANDRIA, VA

Mr. GUIDA. Ladies and gentlemen, good morning.

I do not have a written statement, and I intend to adhere strictly to the 10 minutes I have been allotted.

I represent the National Mental Health Association. We are a voluntary health organization that is concerned about raising awareness, fighting the social stigma that is attached to mental illnesses, and raising awareness about the need for health care, specifically mental health care, for these individuals.

You folks are confronted with a lot of very serious policy issues as they relate to Medicaid beneficiaries and the provision of services for these individuals within a managed care setting, and I want to step back a little bit and maybe try to weave some of the policy issues you are confronted with with some of the day-to-day realities of the individuals whom we are all concerned about here at the table.

There are today about 13 million Medicaid beneficiaries in some sort of managed care plan, in some sort of Medicaid managed care arrangement. The vast majority of these individuals are low-income women and kids, former AFDC recipients, primarily—now, I guess, TANF recipients, or whatever we are calling the former AFDC program today.

In most cases, States have not, or have moved more slowly in enrolling disabled populations into managed care. That is not the case with people with mental illness, unfortunately. There, the States have moved with great vigor to enroll people with very severe mental disorders—schizophrenia, manic depression, major clinical depression, obsessive-compulsive disorder—into various managed care arrangements. They have also moved with great vigor to move children with serious emotional disturbances—youngsters in the foster care system, youngsters in the special education system, into managed care arrangements to control their costs.

So that more or less, for millions of Americans with severe mental illness, the vast majority of those individuals depend upon Medicaid for the provision of both their acute care medical services—psychiatric visits, access to prescriptions for psychotropic drugs—as well as to an array of community-based services that are necessary to sustain that individual in a community.

So, what are we talking about here? OK. Let's take schizophrenia as an example. Ladies and gentlemen, when you have schizophrenia, there is a series of symptoms that relate to the disorder. Now, schizophrenia is a biologic imbalance in the brain. Individuals with schizophrenia have a genetic predisposition to it. What occurs in most cases, particularly in the most severe forms of schizophrenia, is that the disease is marked by delusions, hallucinations, disorganized speech, and grossly disorganized or catatonic behavior.

Now, the age of onset for schizophrenia is 18 to 21. In most cases, as a result, you will probably never hold a job, or you will never hold a job involving very serious, long-lasting, cognitive interaction. Your ability to interact with your family, your ability to hold a job, your ability to go to school, are all severely impaired by the disorder. In fact, schizophrenia along with the other major mental illnesses—obsessive-compulsive disorder, often major clinical depression—are recurrent, persistent and chronic illnesses. So what that means is that you are going to have that for the rest of your life, and because of its recurrent nature, you will spend a significant portion of your time, or at least some portion of your time, in a psychiatric facility, either in a State-owned and operated States hospital or in a private psychiatric facility, because you will go through recurrent crises depending upon how you respond to the psychotropic medications—Haldol, for example, Resperdal, or one of the latest medications—that are given to you to control your symptoms.

So you are going to both spend a significant amount of time in a psychiatric facility, and you are going to need an extensive array of support when you are not in a 24-hour environment.

Now, put yourself in the position of that individual for just a moment, OK? You are "Eddie Dibarcolo." You just stepped out of a State psychiatric facility in the State of Connecticut, my home State. You have been diagnosed with a severe mental illness, let's say schizophrenia. You are on a major psychotropic drug in order to control the symptoms of that disorder. You are a severely impaired individual in most cases. You may have spent a significant part of that year in a State psychiatric facility.

What do you need? You need supported housing. Odds are you are not going to be able to live by yourself. You are going to need some sort of supervised environment where someone can look after you and where someone can engage in medication management. Medication is a very important part of your life.

You need psychiatric rehabilitation. What does that mean? You need training in how to dress in the morning, how to put your shoes on, how to cook, how to go to work, how to take a bus to get to work; and you often need a very extensive array of community-based services—partial hospitalization, emergency crisis services, very intensive case management, because you need someone who in most cases is someone hired by the State, that person is receiving Medicaid reimbursement through the State, through the case management option, to facilitate and to coordinate all of these services. You are certainly not going to be able to do it yourself given the fact that you have a very severe mental disorder.

OK. The difficulty is as follows—and this is just speaking for myself and for the National Mental Health Association. Managed care is and was developed as an acute care medical service delivery system. It was designed essentially for a healthy population, with a very heavy preventive focus, to reduce acute care medical services. The types of service that we have just talked about, all of which are now financed through Medicaid with the exception of supported housing, naturally, but all the stuff I just talked about in one way or another, through some State option or another, is financed through the Medicaid program, are not acute care in nature. They are long-term services. Once again, you are going to need this type of intervention for the rest of your life.

Now, there is some question as to whether managed care can handle the provision of these types of very intensive services over an extended period of time to a chronically ill population. In the mental health field, States are the insurer and last resort; all of you now, or probably most of you in the room, are covered by private health insurance. If, for whatever reason, you lose your private health insurance, often because you have developed a severe mental illness while you are on private health insurance and you have blown through the coverage limits in that policy—the number of days you are given in a private psychiatric facility, the amount of outpatient days number about 20 days, you cannot make the copayments on your insurance policy, you have hit the lifetime ceiling on the policy—if you lose your private health insurance, State and county government, assisted by the Medicaid program, will be responsible for your care. They are the insurer of last resort. Many of these States and many of these counties are reducing their public sector mental health spending, the money of last resort to facilitate services to you, into a request for proposals and shifting that RFP out to bid. The bidders are in many cases private, for-profit, managed care companies that feel like they can (a) provide you with the services that you need of the type that I just discussed, and (b) hopefully, cover administrative expenses and make a profit.

Now, the Finance Committee has responded in a number of different ways in its mark to this development that I just described. For example, Senator Kerrey sponsored an amendment which was also sponsored in the House Commerce Committee that prevents mandatory enrollment of children with special needs in Medicaid managed care plans. That encompasses kids with cerebral palsy, spina bifida and autism, including the kids I represent, kids with serious mental and emotional disturbances. The mark or the bill as amended bars the enrollment of these kids into mandatory managed care plans. The State would have to seek a special waiver from the Federal Government to enroll these kids in managed care arrangements.

Senator Grassley successfully engineered an amendment that requires the Secretary, with regard to the rest of the disability population—and people with special needs who depend upon Medicaid, the rest of the disability population is very substantial—people with very severe mental retardation; the folks that Tony just discussed; kids with developmental disabilities; people with AIDS, and a variety of individuals with disabilities who are not covered by the Kerrey Amendment I just discussed.

Senator Grassley engineered a provision that would require the Secretary to issue special guidelines that would specifically govern the Secretary's examination of State plan amendments as the States file amendments with the Secretary to move these populations into managed care arrangements.

I see that my time is up, so I will be available for questioning.

Ms. CHRISTENSEN. Thank you.

[The prepared statement of Al Guida follows:]

National
Mental Health
Association™

Chair of the Board, Robert Klepfer, Jr.
President and CEO, Michael M. Faenza

1021 Prince Street, Alexandria, VA 22314-2971 Phone 703/684-7722 Fax 703/684-5968 Internet - http://www.worldcorp.com/dc-online/nmha

June 23, 1997

AL GUIDA'S TALKING POINTS FOR SENATE AGING COMMITTEE'S PEOPLE WITH SPECIAL NEEDS FORUM

General Theme: Managed care has a long -- and largely successful -- track record in providing acute care medical services to an essentially healthy enrollment base. However, as these plans compete to secure public sector Medicaid contracts involving direct service delivery to people with disabilities and children with complex medical conditions, a number of questions emerge:

1.) Do medical necessity criteria need to be adjusted?

Today, Medicaid finances an array of services that are designed to: (i) sustain and slowly improve the functional capacity of people with disabilities and (ii) assist disabled children in attaining and maintaining developmental milestones.

Specifically, Medicaid pays for developmental services like occpuational therapy, physical therapy and speech language pathology for children with mental retardation, cerebral palsy, cystic fibrosis and autism. In most cases, these services are furnished over a period of years and produce relatively slow improvements in functional capability over time.

NMHA believes that public sector medical necessity criteria must be modified so that these long-term care services will continue to be provided.

2.) Do case management definitions need to be adjusted?

Public sector and private sector "case management" are two very different creatures. For example, in most cases, HMOs provide assistance to enrollees in navigating their acute care medical network. On the other hand, "intensive case management" -- financed through Medicaid at state option -- facilitates access for people with disabilities to an array of community services, rehabilitation programs, supported housing opporunties, and peer support groups.

It seems clear that these two world views need to be reconciled as Medicaid managed care movements forward.

3.) What services will be financed by HMOs that win Medicaid contracts?

While many of the community-based interventions in the mental health field are non-medical in nature, they are essential to sustaining individuals with severe mental illnesses in the community. Psychiatric rehabiliation, financed through the rehabiliation option, is a prime example. NMHA strongly believes that managed care firms should develop mechanisms to accredit these interventions -- and most importantly -- strengthen the capacity of the community-based system by investing in such programs.

Kathy.

STATEMENT OF KATHLEEN H. MCGINLEY, ASSISTANT DIRECTOR OF GOVERNMENTAL AFFAIRS, THE ARC

Ms. McGINLEY. Good morning. It is a pleasure to be here. I am Kathleen McGinley, and I am assistant director of governmental affairs for The Arc. The Arc is a national organization on mental retardation, and many of you may know us by one of our previous names, which was the Association for Retarded Citizens. We have had a series of names over the last 50 years that reflect the movement in the field of mental retardation.

Before I start to talk, I am going to talk about people with developmental disabilities and mental retardation, and I have brought a number of handouts. One is the definition of "developmental disabilities," and if you get that—it is a pink handout—it will show you the broad range of people encompassed in this category. I have also brought The Arc's resolution on managed care and long-term supports, which reflects many of the things that Al said and I brought the CCD principles on managed care for people with disabilities.

The issue of managed care and people with special needs is an issue that has been under discussion for a long time in the area of developmental disabilities and mental retardation. This morning, I want to take some time to give you some general information about some of the health and long-term services needs of the children and adults who fit—and I do not know if "fit" is a good word—the definition of developmental disabilities, because it is such a broad group of people. Then I want to talk about some specific concerns that we have about managed care which we see sometimes as having goals that are totally the opposite of the stated goals of the field of mental retardation.

The first thing I want to do is go through the definition, and if you do not have a copy of the definition in front of you, let me just go through a few parts of it and give you some examples of people with developmental disabilities.

A developmental disability is a severe, chronic disability of a person 5 years of age or older which is attributable to a mental or physical impairment or combination of mental or physical impairments, manifested before the person reaches the age of 22, likely to continue indefinitely, resulting in substantial functional limitations in three or more areas of major life activity, reflecting the person's need for a combination and sequence of special treatment or services that are of lifelong or extended duration, individually planned and coordinated.

Some of the people who fit this definition are people with mental retardation, cerebral palsy, autism, spina bifida, epilepsy, emotional disturbance, spinal cord injuries before the age of 22, so it is a very, very broad group of people.

Because it is such a broad group of people, I am going to concentrate more on the needs of children and adults with mental retardation because that is really who I advocate for.

Mental retardation is not a disease. It is not something that can be cured. Not so many years ago, it was believed that there was something wrong with people with mental retardation, that they were sick, or that their disability was a punishment on their parents for doing something bad. It was no wonder, then, that there was not anything available for people in the community, and so many people with mental retardation in the past ended up in large institutions, way outside of town. Because of this history, it is no wonder that discrimination and stigma still abound.

In a lot of ways, times have changed. Most professionals in the field of mental retardation know that what we must do now is work to ensure that society and the community offer the person with mental retardation the opportunity to develop skills be healthy and independent. The person with the disability, their family, friends and the professionals, in the best world would work together on this goal.

The key component of this new approach is that it is person-centered, and it focuses on the needs, desires and choices of the individual—or a surrogate, if the person's disability limits his or her choice-making skills—and we call this self-determination. The control is in the hands of the individual consumer as much as it possibly can be, and that is where we say where we are now. But the specter of the past still haunts us and one of the places where it is particularly haunting is in the area of health care.

For years, people with mental retardation and related disabilities have had an extremely difficult time finding doctors, dentists, gynecologists and other medical professionals to serve them. There have been many reasons for this—people were locked away so mainstream doctors did not know them; people were locked away and medical education ignored their existence; people were often considered harder to treat because their physical and mental conditions required doctors and dentists and others to take more time and more care, and to explain things simply and in detail.

People who are elderly often have these same kinds of needs, but they are a more well-known population, and—I hate to say it—but they often have a lot better health insurance than people with mental retardation.

Now that children with mental retardation are growing up at home and going to school in the community and living and working in the community, they are becoming more known to the medical profession. Families have found doctors and dentists and therapists for their children who finally care about them. Adults have found dentists and gynecologists who care about them and treat them without fear. The possible loss of this relationship if they are forced into managed care is one of the major concerns of people with mental retardation and their families.

Many of the needs of these individuals are the antitheses of some of the manifestations of managed care. They need access to a number of medical professionals. They need specially trained professionals or professionals who have developed expertise in working with them. They need things explained to them in clear detail and, as I said earlier, it may take a long time for a person with mental retardation or another disability to go to the doctor; it is not a quick, in-and-out visit.

As I said earlier, mental retardation is not something that can be cured, and many of the health and health-related needs of people with mental retardation do not lead to a cure—they may not even lead to an improvement—but they may be critically necessary to help ensure that that person can continue to live or work in his or her home community. Some things like speech therapy or physical therapy, which numerous insurance and managed care plans limit, may be lifelong needs for certain persons, and may make a difference between whether that person can have a job, stay in the community, maintain their friends or, if they lose their skills, their mobility skills, their communication skills, they may be isolated and have many more problems.

As to the issue of the maintenance versus a cure, the definition of "medical necessity," which is used to guide what health insurance and managed care companies cover, is one of the critical issues to people with developmental and other disabilities. Actually, the CCD Health Task Force has developed a really broad definition of medical necessity which we would be happy to share with anybody.

Some of the other major concerns of people with mental retardation in relation to managed care are marketing and the need for marketing regulations to ensure that people who have cognitive limitations, as well as other people, are not taken advantage of; understandable materials and information—in past years, it has been very politically correct to print everything in many foreign languages; we would like to see things printed in plain English. This would help not just people with cognitive disabilities, but people who have low literacy skills.

Another critical concern is the lack of control or choice, which people with mental retardation and their families have fought for so hard over the years.

The final two points that I want to make are related to consumer protections and civil rights. The first is the critical role that Federal oversight currently plays in protecting the lives of children and adults with mental retardation. The importance of this Federal oversight role cannot be underestimated. For people with mental retardation and their families, this is a basic concern. For many years, States ran large and dangerous institutions for people with mental retardation. Most often, they were places where people spent their whole lives, were dehumanized, not educated or helped to acquire job skills; they did not have access to decent health services—in fact, sometimes we know they were subjected to medical experimentation—they were abused and at times, deaths occurred under suspicious circumstances.

When Federal funds were involved in the delivery of these so-called services, the Federal Government then had oversight rights, and it was these oversight rights that helped stop these abuses and also helped to lead to the closure of most of these large and inhumane institutions.

The last point I want to make about a major area of concern in relation to managed care and people with developmental disabilities is the quality of life issue. If the managed care system is permitted to be for-profit and cost-driven and not individual-driven, then we are concerned that the tendency will be for lower-cost people to be the best patients. In the 1970's, it was discovered that doctors were withholding treatment from certain infants because they were disabled. These doctors were making decisions based on their definition of quality of life. One particularly gruesome situation was in a hospital in Oklahoma where it was found that infants with Down Syndrome were being left to die.

In 1985, the Department of Health and Human Services published the Baby Doe regulations, which stated that doctors must treat all infants with life-threatening conditions unless one of three conditions is met.

I bring this issue up today because a recent article in the Journal of Pediatrics reported that more than 10 years after the Baby Doe regulations were published and almost 25 years after the original article on the withholding of treatment by doctors, that withholding and non-treatment still goes on, and selective non-treatment of marginally viable or severely handicapped infants continues to be a vexing ethical dilemma for neonatologists. It is of concern to us that a health care system run on the philosophy of cost savings would appear to make these kinds of decisions even more difficult.

In summary, I just want to say that children and adults with mental retardation and other developmental disabilities have a wide range of needs, and our major concern is that as major policy decisions are being made right now, that people consider the needs of people at the same time they consider the needs of the States.

Thank you.

[The prepared statement of Kathy McGinley follows:]

MANAGED CARE AND LONG TERM SUPPORTS AND SERVICES

Adopted by the Delegate Body
The Arc National Convention
Louisville, Kentucky
November 16, 1996

WHEREAS, 2.8 million Americans with mental retardation and other developmental disabilities depend upon long term supports live and participate in their community, and

WHEREAS, long term supports are defined as needing assistance in either activities of daily living (ADLs) or instrumental activities of daily living (IADLs), and

WHEREAS, the average costs of community based supports per individual are lower than yearly costs for institutional care, and

WHEREAS, The Arc firmly believes that institutional care is no longer necessary or appropriate for anyone, regardless of the type or severity of a person's disabilities and

WHEREAS, nationwide federal and state governments are concerned about the rapidly rising costs of long term supports, and managed care is being considered in some states as a methodology to contain the rising costs of long term supports, and

WHEREAS, managed care has only been broadly applied in the areas of primary and acute care as a possible method of cost containment, and

WHEREAS, there is very little experience with managed care and people with disabilities, and most states utilizing managed care have yet to include people with mental retardation and other developmental disabilities in their systems, and

WHEREAS, data demonstrate that in those few states which have included people with disabilities in their managed care programs, the involved consumers have faced major difficulties, and

WHEREAS, there has been ample criticism of existing primary and acute care managed care services and systems, and

WHEREAS, there has been increased public discomfort with managed care due to loss of choice and consumer control, the inability to access necessary services, and the growing appearance of excess profits in an industry that generally measures effectiveness based on cost not quality, therefore

BE IT RESOLVED that, given the concerns expressed above, The Arc strongly advocates that states and other entities use extreme caution if and when they explore a managed care approach to long term supports;

BE IT FURTHER RESOLVED that The Arc in each state be actively involved to determine if a managed care system for long term supports for people with mental retardation and other developmental disabilities is an appropriate fiscal strategy in that state;

BE IT FURTHER RESOLVED that if a managed care system for long term supports for people with mental retardation and other developmental disabilities is deemed appropriate, such system must:

- be designed to meet the life needs of people with mental retardation and other developmental disabilities in an individualized manner, not based on a medical model, and provided by qualified staff;
- be designed to ensure maximum control by people with mental retardation and other developmental disabilities and designed to maximize individual choice to live freely and successfully in the community;
- be designed to include and involve all stakeholders, especially consumers, families, and advocates, in a meaningful way in all stages of the process, including any transition which would alter the current long term supports system;
- be fully funded, independently of primary and acute care funding, and ensure access to long term supports and services;
- be affordable to the individual, not burdening him/her or family members with inequitable and disproportionate costs which limits access to supports and services;
- be of high quality and designed to measure success based on quality outcomes, not cost savings;
- be designed to improve services and supports in conjunction with cost containment measures without sacrificing the needs of the individual;
- be designed to ensure that cost savings realized are invested primarily in providing long term supports and services to individuals and in reducing waiting lists for eligible beneficiaries and not in excess profits or in shifting funds to primary and acute care;
- be independent of, but coordinated with, the primary and acute care system, and free of conflict of interest, so that individuals receive high quality and appropriate long term supports and services when needed.

Consortium for
Citizens with
Disabilities

Jeff Crowley *202-898-0414*
Bob Griss *202-842-4408*
Kathy McGinley *202-785-3388*
Peter Thomas *202-466-6550*

June 1997

THE CONSORTIUM FOR CITIZENS WITH DISABILITIES HEALTH TASK FORCE PRINCIPLES FOR MANAGED CARE FOR PEOPLE WITH DISABILITIES

The CCD Health Task Force "**Principles for Health Care Reform from a Disability Perspective**" have been used since their development in 1991 to assess the ability of health care reform measures to meet the needs of people with disabilities. The CCD asserts that any effort to reform the nation's health care system must be built on five basic principles: **non-discrimination, comprehensiveness, appropriateness/choice, equity, and efficiency.**

This means that:

- both the public and private health care systems must not discriminate against people with disabilities;

- these systems must make a full range of health and health related services and supports available to people with disabilities in an efficient manner based on their individual needs and choices and

- people with disabilities must not be burdened with inequitable and disproportionate costs which limit their access to services

Policy makers at both the national and state levels must recognize that there are at least 43 million people with disabilities in the United States, as well as a large number of others with special health care needs. This includes individuals of all ages with physical and mental impairments, conditions, or disorders that are severe, acute, or chronic which limit or impede their ability to function. Therefore, reform efforts must take into consideration the needs of people with disabilities.

Currently, the role of managed care occupies center stage in the health care debate. Managed care is viewed by many as a means to control health care costs while at the same time promoting good health. However, this is not the view of the disability community. Reports from consumers with disabilities indicate that access to necessary services is either denied or severely limited by managed care organizations because of a lack of understanding of the needs of individuals with disabilities.

Building on its earlier work, the CCD Health Task Force has developed the following managed care principles to help consumers and advocates evaluate current and emerging managed care proposals, practices, standards and guidelines and ensure their appropriate application to people with disabilities. This is a set of guiding principles. It is not a "cook book" for the perfect managed care system. These principles should be viewed only as a starting place by advocates who are working to ensure that managed care systems meet the varied needs of children and adults with disabilities and their families.

Issues in managed care concerning long term services and supports for people with disabilities are not expressly addressed in this document. Other CCD materials address these issues. However, the CCD wants to stress that if a managed care entity is responsible for any long term services and supports, these must be provided in accordance with best practices and emphasize community-based, consumer directed services. Long term services must not become overly medicalized because a health care entity is responsible for payment. Consumers of long term services must be given choices and a full range of quality assurance measures must be available based on individual needs and personal preferences about types, methods, providers, and sites of services.

Principles For Managed Care For People With Disabilities

The CCD believes that if managed care systems/plans are to meet the needs of people with disabilities, they must embody the following principles.

Consumer Participation

- Managed care systems/plans must ensure that all key stakeholders, including individuals with disabilities, family members, support agencies, providers, advocates, and others are enlisted in designing, implementing, and overseeing the operation of both public and private managed care systems and plans.

- Managed care systems/plans must not encourage placement in institutions but, instead, encourage the provision of services that support people to live as independently as possible and to participate in the every day life of the community.

Consumer Choice

- Managed care systems/plans must expand, not diminish, opportunities for people with disabilities and their families to choose services and supports that will improve the quality of their lives.

- Managed care systems/plans must be structured in a manner that decentralizes decisionmaking and promotes innovation in providing appropriate services and supports to people with disabilities.

- Managed care systems/plans must provide enrollees with a choice of plans or offer an affordable point of service option. However, the availability of a point of service option must not mean that managed care plans do not have the responsibility to provide appropriate care or pay for an out-of-network referral if the managed care plan cannot provide a service.

Appropriate Definition of Medical Necessity

- For individuals with disabilities, the term "medical necessity" must be defined in the broadest manner possibleto ensure access to all appropriate services and supports that can enable a person with a disability to function in the community as independently as possible.

Equitable Financing Mechanisms

- Any financing mechanism that may directly or indirectly constrain access to appropriate services must be prohibited.

- Managed care systems/plans must not include financial incentive procedures that directly or indirectly restrict access or deny adequate and appropriate services. Systems/plans that contain incentives for individual providers regarding utilization of services must not link financial rewards/penalties with individual treatment decisions.

- Managed care systems/plans must have "stop-loss" provisions or limits to risk that are mutually agreed upon by providers and plan sponsors when provider groups (particularly small groups) assume financial risk for the cost of specialty care, ancillary services, and/or hospital care.

- Additional amounts of provider time or effort required by people with disabilities or chronic illness must be compensated commensurate with the additional effort required, either as a component in the capitation agreement or through some mutually agreeable financial arrangement.

- Managed care systems/plans must collect utilization data over periods of time sufficient to identify patterns of risk. Risk sharing arrangements across a group of providers must also be based on the performance of the provider group over periods of time.

Consumers Benefit from Cost Savings

- Managed care systems/plans must be designed to ensure that cost savings realized through the more efficient administration of services are invested primarily in providing services and supports and reducing waiting lists for eligible beneficiaries.

Appropriate Services and Benefits Available

- Managed care systems/plans must offer a comprehensive benefits package that meets the needs of people with disabilities and special health care needs. This includes such basic benefits as prescription drugs, preventive services, rehabilitation services, durable medical equipment, orthotics and prosthetics, and mental health services

- Managed care systems/plans must offer all necessary benefits, services, and supports across multiple settings, such as home, school, work. There must be no arbitrary limitations on service settings.

- Managed care systems/plans must not include disincentives, financial or otherwise, to the provision of services in home and community-based settings.

- Managed care systems/plans must be structured to ensure continued, appropriate access to health and health related services.

- Services should be provided not only to treat acute and chronic conditions but also to promote and maintain health and optimum functioning and prevent deterioration and secondary disabilities.

- Managed care systems/plans must have specific limits on waiting times for first appointments and for specialty referrals. To assure geographic accessibility of services, there must also be established standards for travel times and distances to both primary and specialized services.

Access to Specialty Services

- Managed care systems/plans must provide for access to and the effective coordination of specialized services with other systems/supports on which people with disabilities rely.

- Managed care systems/plans must offer people with disabilities and special health care needs the option of having a specialist as their "gatekeeper" in the system/plan. This specialist would provide both necessary specialized services -- at the specialized rate -- and primary care services -- at the lower primary care reimbursement rate.

Strong Quality Assurance Measures

- Managed care systems/plans must comply with the protections offered by Section 504 of the Rehabilitation Act of 1973, as amended, the Americans with Disabilities Act, and other civil rights statutes.

- Managed care systems/plans must provide participants with clear information on policies, procedures, grievance mechanisms, and appeals and must ensure consumer participation in the establishment of such procedures.

- Managed care systems/plans must provide access to independent organizations that provide ombudsman and rights protection services.

- Managed care systems/plans must have in place a mechanism for responding to adverse utilization review by including appropriate grievance and appeals mechanisms.

- Managed care systems/plans must include mechanisms for avoiding discrimination in the provision of services. This includes the prohibition of arbitrary limits through reasonable accommodations in such areas as benefits, location of services, length of treatment, and geographical location.

- Managed care systems/plans should be required to provide health care services in accordance with nationally accepted prevention and treatment protocols, e.g. protocols for prenatal care, well-baby care, and childhood immunization schedules, or current best-practices.

- Managed care systems/plans must communicate to enrollees and prospective enrollees which services are covered and which are excluded in a consistent format that is clear and easily understood. Included must be information on co-payments, deductibles, the existence of any utilization review requirements, as well as any financial incentives that restrict or require the use of specific providers, facilities, services, or products.

- Managed care systems/plans that utilize provider risk sharing arrangements or other incentives related to utilization of services must have established mechanisms in place for monitoring quality of care.

- Managed care systems/plans must include the option to disenroll for those participants who are not receiving adequate and timely services.

- Managed care systems/plans must be required to collect and report a uniform set of data that allows public officials and consumers to evaluate and compare performance, including longitudinal data to measure outcomes for people with disabilities. Community agencies and consumers must be involved in design of and ongoing participants in quality assurance systems which focus on appropriate outcomes for the individual.

- Managed care systems/plans must have strict quality assurance provisions that require internal and external review mechanisms by independent assessors and the results of these reviews should be available to consumers to assist them in choosing a managed care plan. Individually focused outcome reviews should be a key component of this process.

Consumer Education

- In order to avoid marketing abuses by managed care systems/plans, states must be required to prohibit direct enrollment by plans and instead set up an independent enrollment and counseling process which permits enrollees -- in the public and private markets -- to explore options in choosing among plans. All such efforts must be designed to respond in a non-discriminatory manner to the varying abilities and needs of people with disabilities.

- Managed care systems/plans must disclose in a clear and easily understood manner to enrollees and prospective enrollees the plan's policy with regard to withholds, privileges, denials of payment, and any other mechanism with a utilization/financial incentive link.

- Managed care systems/plans must establish a means by which consumers and payers can accurately evaluate and effectively choose plans on the basis of measured results

For more information, contact one of the co-chairs of the CCD Health Task Force listed at the top of page one.

NATIONAL
ASSOCIATION
OF
DEVELOPMENTAL
DISABILITIES
COUNCILS

1234 Massachusetts Avenue, NW • Suite 103 • Washington, DC 20005 • 202-347-1234

What is a Developmental Disability?

A "developmental disability" is a severe, chronic disability of a person five years of age or older which –

1. is attributable to a mental or physical impairment or combination of mental or physical impairments;
2. is manifested before the person attains age twenty-two;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in three or more of the following areas of major life activity:
    a) self-care,
    b) receptive and expressive language,
    c) learning,
    d) mobility,
    e) self-direction,
    f) capacity for independent living, and
    g) economic self-sufficiency and
5. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated, (except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided).

Examples of developmental disabilities include children and adults with a wide range of diagnoses, including mental retardation, cerebral palsy, autism, spinal cord injury and severe head injury, so long as the condition began before age 22 and therefore affected the person's development.

Ms. CHRISTENSEN. Thank you, Kathy.
Nancy.

STATEMENT OF NANCY LEONARD, MSW, LCSW CARE MANAGER, CONNECTICUT COMMUNITY CARE, INC., ON BEHALF OF THE ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, WASHINGTON, DC

Ms. LEONARD. Good morning. I represent the frail elderly, particularly those diagnosed with Alzheimer's disease. I would like to go over some facts and figures in regard to frail older adults and those in particular affected with Alzheimer's disease. I will "walk" you through a real case to demonstrate some "best practice" issues and some of the obstacles those of us "in the trenches" experience on a daily basis.

These facts and figures provide a snapshot of long-term care issues. One in five Americans over the age of 50 may need long-term care in the next year, according to the Journal of the National Association for Home Care. Most of those needing long-term care receive their care at home; only 4.2 percent of people over 65 are in nursing homes. Only 20 percent of those 80 and older are in nursing homes.

Expenditures for nursing homes still consume a major share of long-term care spending. In FY 95, Federal and State governments spent over $49 billion in Medicaid dollars, of which $40 billion went to nursing home care, and only $9.5 billion was spent on home and community-based care. Medicaid is the major source of public funding for long-term care services.

Allow me to focus on one disease entity particular to our older citizens, which is Alzheimer's disease. Four million people in the United States have Alzheimer's disease. Fourteen million people in the United States will have Alzheimer's disease by the middle of the 21st century. The disease process may begin in the brain as much as 20 years before the symptoms of Alzheimer's appear.

The total annual cost of caring for victims of Alzheimer's disease in the United States is estimated to be $100 billion. This makes Alzheimer's the third most costly disease after heart disease and cancer.

I would like to illustrate the points that Susan, through her fax, asked us to bring forth by discussing my client, Mrs. M.

Mrs. M. is a retired teacher living alone on her teacher's pension. She lives at home, with a diagnosis of cancer of the bowel, with a colostomy, diabetes, and dementia. She takes a total of six medications twice daily. Because of her dementia, she cannot be left alone.

Mrs. M. is disoriented to person, time and place. She demonstrates impaired judgment by leaving pots on the stove for long periods of time until they burn. She demonstrates behavior problems such as suspiciousness, wandering, sleep disturbances and hallucinations. She requires assistance with bathing and cueing for dressing.

She is unable to perform any of her household management such as cooking, cleaning, and money management. She is unaware of her own health status, and she cannot manage her medications appropriately.

Mrs. M.'s care plan is quite complex. She uses a combination of companions, adult day care, home health aides, meals-on-wheels, and nursing services, all of which are coordinated through a care manager. She receives care 7 days a week. Mrs. M. goes to an adult day care center twice a week on Tuesdays and Thursdays, and throughout the week, Monday through Sunday, there is a homemaker/companion who visits Mrs. M. in the evenings to prepare meals and to ensure that she has taken her evening medications. Mrs. M.'s son spends the night in order to secure Mrs. M.'s safety in the evening.

Mrs. M.'s care requires multiple service providers to support her at home. The complexity of assessing, coordinating and monitoring her needs and multiple services requires the skill of a highly trained nurse or social worker. The care manager juggles the complex issues to establish a plan of care to support both the client and caregivers.

Mrs. M. requires providers with an adequate understanding of geriatrics and dementia care. For example, on days that Mrs. M. needs a bath, the home health aide is able to utilize the skills that she has learned in her dementia training provided by the care manager. She can decrease the client's agitation by approaching Mrs. M. from the front and not scaring her and giving clearly stated directions.

Mrs. M.'s plan of care consists of "low-tech, high-touch" service such as companion, homemaker, and meals-on-wheels. All providers of her care are oriented to basic dementia care in order to provide an environment that is supportive, nonthreatening and medically safe.

The care manager negotiates with providers to identify resources to address the special needs of this population. For example, a registered nurse with dementia training was selected. The nurse has utilized her specific assessment techniques to try to understand any underlying medical conditions that might be occurring.

Mrs. M.'s attendance at an adult day care center provides a wonderful service to her. She is able to capitalize on her strengths, and she is able to teach a class to some of the other participants at the day center. The day care center Mrs. M. attends is exceptional and provides an excellent example of a highly trained staff and the organization's desire and commitment to provide dementia-capable services. They exhibit high standards of practice and the flexibility that is needed for someone like Mrs. M.

All of Mrs. M.'s care is coordinated by a care manager with a specialty in dementia. She works collaboratively with Mrs. M.'s primary doctor, nurse, day care provider, homemaker, companion, and the meals-on-wheels driver, as well as the neighbor. Mrs. M. is unable to act in her own best interest; therefore, her son was appointed as conservator of person or guardian. Her son is an integral member of the dementia care team that works together to support Mrs. M.'s independence. The primary responsibility of the care manager and the son is to assess, coordinate and monitor the plan of care by coordinating and consulting with all team members on a regular basis.

Managing someone like Mrs. M. is a challenge because securing payment for services in our current system is almost impossible.

Because Mrs. M. does not present a need for skilled service, she does not qualify for Medicare coverage. The ironic situation in Mrs. M.'s case is that the minimal plan of care she is receiving is not currently recognized as, or valued in, our Medicare system.

A higher level of care will need to be implemented if Mrs. M. deteriorates and becomes Medicare-eligible. Should she need long-term care in a nursing home it is likely she will need access to Medicaid because she is "spending down" her private funds. Therefore, there is no method of payment for the "low-tech, high-touch" care that Mrs. M. currently requires.

In summary, the following represent "best practice" in the context of managing a frail older adult in the community. It is crucial that the providers of care have a working knowledge of geriatrics and the care of those with Alzheimer's disease and related disorders. These providers must be able to provide dementia-capable services, which include substantial support and knowledge in the area of caregiver stress; the plan of care is consumer-driven, and the decision making process includes the individual and/or responsible party, and the management be coordinated through an interdisciplinary team of professionals, paraprofessionals, family members and/or responsible parties.

The following represent obstacles in obtaining services; securing payment for services in our current system for someone who needs ongoing custodial care is almost impossible. The issue of needing skilled care such as registered nurses, home health aides, physical therapy, and occupational therapy versus custodial care, such as companions, homemakers, or day care, is a significant problem for people suffering from Alzheimer's disease. An individual with Alzheimer's disease could be managed in a more cost-effective manner if the system were designed as a combination medical—social model of care.

Providers of care are not trained in providing the appropriate level of care, especially in the area of dementia care.

The lack of a coordinated service delivery system fosters the current expensive and complex system of long-term care.

My recommendations regarding managed care models for frail elders include. First, managed care models must recognize that the older adult and his or her informal support network of family and friends are the central focus of the plan of care.

Second, managed care models must provide quality services which respond specifically to the needs of frail elders. While the high-tech interventions of the last decades respond to the needs of some populations, services for elders must include "low-tech, high-touch" services such as homemaker, companion, home-delivered meals and day care.

Third, managed care organizations must utilize a comprehensive care management model in order to identify the unique strengths and deficits in each clinical situation, and to maximize all available community resource options.

Fourth, managed care models must provide appropriate access to specialty care when necessary. In view of the increasing prevalence of Alzheimer's disease and related disorders, it is imperative that the services of geriatricians, geriatric psychiatrists, neurologists, nurses and social workers be available to address the needs of these elders and their caregiving families.

Fifth, special attention must be paid to the role of respite care services for informal providers. It is nationally recognized that a full 80 percent of all care for frail elders is provided by their informal care systems—spouses, children, grandchildren, as well as significant friends and neighbors. Without adequate respite care, informal caregivers are unable to continue their vital role in the long-term care system.

Sixth, finally, managed care models must address the current institutional bias in the long-term care system, recognizing the desire of the elderly to remain in the community, to remain in their own homes whenever possible. Managed care models must include a full range of community care services in their benefit plans.

Thank you, and I look forward to entertaining any questions.

[The prepared statement of Nancy Leonard follows:]

ALZHEIMER'S ASSOCIATION
Someone to Stand by You

GOOD MORNING

MY NAME IS NANCY LIBERATORE LEONARD. I AM A LICENSED CLINICAL SOCIAL WORKER WITH 11 YEARS OF EXPERIENCE AND PRACTICE AT CONNECTICUT COMMUNITY CARE, INC. CCCI IS AN INDEPENDENT STATEWIDE NOT FOR PROFIT CARE MANAGEMENT ORGANIZATION WITH OVER 20 YEARS OF EXPERIENCE IN HELPING FRAIL OLDER ADULTS REMAIN SAFELY AT HOME. I ALSO SERVE AS THE PRESIDENT OF THE NORTHERN CONNECTICUT CHAPTER OF THE ALZHEIMER'S ASSOCIATION. IT IS BOTH AN HONOR AND A PRIVILEGE FOR ME TO TESTIFY BEFORE YOU TODAY.

I REPRESENT THE FRAIL ELDERLY, IN PARTICULAR, THOSE DIAGNOSED WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS.

THESE FACTS AND FIGURES PROVIDE A SNAPSHOT OF LONG TERM CARE ISSUES:

- ONE IN FIVE AMERICANS OVER THE AGE OF 50 MAY NEED LONG TERM CARE IN THE NEXT YEAR, ACCORDING TO CARING MAGAZINE. (THE JOURNAL OF THE NATIONAL ASSOCIATION FOR HOME CARE)
- MOST OF THOSE NEEDING LONG TERM CARE RECEIVE THEIR CARE AT HOME. ONLY 4.2 PERCENT OF PEOPLE OVER AGE 65 ARE IN NURSING HOMES, ACCORDING TO THE 1995 NATIONAL NURSING HOME SURVEY FROM THE NATIONAL CENTER FOR HEALTH STATISTICS.
- ONLY 20 PERCENT OF THOSE 80 AND OLDER ARE IN NURSING HOMES.

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.
[illegible] • [illegible] 20004 • Phone (202) [illegible] • Fax (202) [illegible]

- EXPENDITURES FOR NURSING HOMES STILL CONSUME A MAJOR SHARE OF LONG TERM CARE SPENDING. IN FISCAL YEAR 1995, THE FEDERAL AND STATE GOVERNMENTS SPENT OVER $49 BILLION IN MEDICAID DOLLARS, OF WHICH ALMOST $40 BILLION WENT TO NURSING HOME CARE AND ONLY $9.5 BILLION WAS SPENT ON HOME-AND COMMUNITY-BASED CARE SERVICES. MEDICAID IS THE MAJOR SOURCE OF PUBLIC FUNDING FOR LONG TERM CARE SERVICES.

ALLOW ME TO FOCUS ON ONE DISEASE ENTITY PARTICULAR TO OUR OLDER CITIZENS, ALZHEIMER'S DISEASE.

- 4 MILLION PEOPLE IN THE UNITED STATES HAVE ALZHEIMER'S DISEASE.
- 14 MILLION PEOPLE IN THE UNITED STATES WILL HAVE ALZHEIMER'S DISEASE BY THE MIDDLE OF THE 21ST CENTURY UNLESS SCIENTISTS CAN DISCOVER A WAY TO PREVENT OR CURE THE DISEASE.
- THE DISEASE PROCESS MAY BEGIN IN THE BRAIN AS MUCH AS 20 YEARS BEFORE THE SYMPTOMS OF ALZHEIMER'S APPEAR. A PERSON WILL LIVE AN AVERAGE OF 8 YEARS AND AS MANY AS 20 ONCE THE SYMPTOMS APPEAR.
- THE TOTAL ANNUAL COST OF CARING FOR VICTIMS OF ALZHEIMER'S DISEASE IN THE UNITED STATES IS ESTIMATED TO BE $100 BILLION (NATIONAL ALZHEIMER'S ASSOCIATION). THIS MAKES ALZHEIMER'S THE THIRD MOST COSTLY DISEASE, AFTER HEART DISEASE AND CANCER.

I CAN BEST ILLUSTRATE MY POINTS BY DISCUSSING AN ACTUAL CLIENT.

CASE STUDY - MRS. M.

MRS. M. IS A RETIRED TEACHER LIVING ALONE ON HER TEACHER'S PENSION. SHE LIVES AT HOME WITH A DIAGNOSIS OF CANCER OF THE BOWEL WITH A COLOSTOMY, DIABETES AND DEMENTIA. SHE TAKES A TOTAL OF SIX MEDICATIONS TWICE DAILY. BECAUSE OF HER DEMENTIA, SHE CANNOT BE LEFT ALONE. MRS. M. IS DISORIENTED TO PERSON, TIME AND PLACE. SHE DEMONSTRATES IMPAIRED JUDGMENT BY LEAVING POTS ON THE STOVE FOR LONG PERIODS OF TIME UNTIL THEY BURN. SHE DEMONSTRATES BEHAVIOR PROBLEMS SUCH AS SUSPICIOUSNESS, WANDERING, SLEEP DISTURBANCES AND HALLUCINATIONS. SHE REQUIRES ASSISTANCE WITH BATHING AND CUEING FOR DRESSING. SHE IS UNABLE TO PERFORM ANY OF HER HOUSEHOLD MANAGEMENT SUCH AS COOKING, CLEANING, MONEY MANAGEMENT, ETC. SHE IS UNAWARE OF HER OWN HEALTH STATUS AND SHE CANNOT MANAGE THE MEDICATIONS APPROPRIATELY. MRS. M.'S CARE PLAN IS QUITE COMPLEX. SHE UTILIZES A COMBINATION OF COMPANIONS, ADULT DAY CARE, HOME HEALTH AIDES, MEALS-ON-WHEELS AND NURSING SERVICES, ALL OF WHICH ARE COORDINATED THROUGH A CARE MANAGER. SHE RECEIVES CARE SEVEN DAYS A WEEK. MRS. M. GOES TO AN ADULT DAY CARE CENTER TWICE A WEEK ON TUESDAY AND THURSDAY AND THROUGHOUT THE WEEK, MONDAY THROUGH SUNDAY, THERE IS A HOMEMAKER/COMPANION THAT VISITS MRS. M. IN THE EVENINGS TO PREPARE MEALS AND TO ENSURE THAT SHE HAS TAKEN HER EVENING MEDICATIONS. MRS. M.'S SON SPENDS THE NIGHT IN ORDER TO SECURE MRS. M.'S SAFETY IN THE EVENING.

IN MRS. M.'S CASE, THERE IS A NEED FOR MULTIPLE SERVICE PROVIDERS TO SUPPORT HER CARE AT HOME. THE COMPLEXITY OF ASSESSING, COORDINATING AND MONITORING HER NEEDS AND MULTIPLE SERVICES

REQUIRES THE SKILL OF A HIGHLY TRAINED NURSE OR SOCIAL WORKER. THE CASE MANAGER JUGGLES THE COMPLEX ISSUES TO ESTABLISH A PLAN OF CARE TO SUPPORT BOTH THE CLIENT AND CAREGIVERS. MRS. M. REQUIRES PROVIDERS WITH AN ADEQUATE UNDERSTANDING OF GERIATRICS AND DEMENTIA CARE. FOR EXAMPLE, ON DAYS THAT MRS. M. NEEDS A BATH, THE HOME HEALTH AIDE IS ABLE TO UTILIZE THE SKILLS THAT SHE HAS LEARNED IN HER DEMENTIA TRAINING PROVIDED BY THE CARE MANAGER. SHE CAN DECREASE THE CLIENT'S AGITATION BY APPROACHING MRS. M. FROM THE FRONT AND NOT SCARING HER AND GIVING CLEARLY STATED DIRECTIONS. MRS. M.'S PLAN OF CARE CONSISTS OF "LOW TECH, HIGH TOUCH" SERVICE SUCH AS COMPANION, HOMEMAKER, AND MEALS-ON-WHEELS. ALL PROVIDERS OF HER CARE ARE ORIENTED TO BASIC DEMENTIA CARE IN ORDER TO PROVIDE AN ENVIRONMENT THAT IS SUPPORTIVE, NOT THREATENING, AND MEDICALLY SAFE. THE CARE MANAGER NEGOTIATES WITH PROVIDERS TO IDENTIFY RESOURCES AVAILABLE TO ADDRESS THE SPECIAL NEEDS OF THIS POPULATION. FOR EXAMPLE, A REGISTERED NURSE WITH DEMENTIA TRAINING, WAS SELECTED. THE NURSE HAS UTILIZED HER SPECIFIC ASSESSMENT TECHNIQUES TO TRY TO UNDERSTAND ANY UNDERLYING MEDICAL CONDITIONS THAT MIGHT BE OCCURRING. MRS. M.'S ATTENDANCE AT AN ADULT DAY CARE CENTER PROVIDES A WONDERFUL SERVICE TO HER. THERE SHE IS ABLE TO CAPITALIZE ON HER STRENGTHS AND SHE IS ABLE TO TEACH A CLASS TO SOME OF THE OTHER PARTICIPANTS AT THE DAY CENTER. THE DAY CARE CENTER MRS. M. ATTENDS IS EXCEPTIONAL AND PROVIDES AN EXCELLENT EXAMPLE OF THE HIGHLY TRAINED STAFF AND THE ORGANIZATION'S DESIRE AND COMMITMENT TO PROVIDE DEMENTIA CAPABLE SERVICE. THEY EXHIBIT HIGH STANDARDS OF PRACTICE AND THE FLEXIBILITY THAT IS NEEDED FOR SOMEONE LIKE MRS. M.

ALL OF MRS. M.'S CARE IS COORDINATED BY A CARE MANAGER WITH A SPECIALTY IN DEMENTIA CARE. SHE WORKS COLLABORATIVELY WITH MRS. M.'S PRIMARY DOCTOR, NURSE, DAY CARE PROVIDER, HOMEMAKER, COMPANION AND THE DRIVER OF THE MEALS-ON-WHEELS AS WELL AS THE NEIGHBOR. MRS. M. IS UNABLE TO ACT IN HER OWN BEST INTEREST; THEREFORE, HER SON WAS APPOINTED AS CONSERVATOR OF PERSON (GUARDIAN). HER SON IS AN INTEGRAL MEMBER OF THE DEMENTIA CARE TEAM THAT WORKS TOGETHER TO SUPPORT MRS. M.'S INDEPENDENCE. THE PRIMARY RESPONSIBILITY OF THE CARE MANAGER IS TO ASSESS, COORDINATE AND MONITOR THE PLAN OF CARE BY COORDINATING AND CONSULTING WITH ALL TEAM MEMBERS ON A REGULAR BASIS.

MANAGING SOMEONE LIKE MRS. M. IS A CHALLENGE BECAUSE SECURING PAYMENT FOR SERVICES IN OUR CURRENT SYSTEM IS ALMOST IMPOSSIBLE. BECAUSE MRS. M. DOES NOT PRESENT A NEED FOR SKILLED SERVICES, SHE DOES NOT QUALIFY FOR MEDICARE COVERAGE. THE IRONIC SITUATION IN MRS. M.'S CASE, IS THAT THE MINIMAL PLAN OF CARE THAT SHE IS RECEIVING IS NOT CURRENTLY RECOGNIZED AS, OR VALUED IN, OUR MEDICARE SYSTEM. A HIGHER LEVEL OF CARE WILL NEED TO BE IMPLEMENTED IF SHE DETERIORATES AND BECOMES MEDICARE ELIGIBLE. SHOULD SHE NEED LONG TERM CARE (NURSING HOME) IT IS LIKELY SHE WILL NEED TO ACCESS MEDICAID. THEREFORE, THERE IS NO METHOD OF PAYMENT FOR THE "LOW TECH, HIGH TOUCH" CARE THAT MRS. M. REQUIRES. IN SUMMARY, THE FOLLOWING REPRESENT THE BEST PRACTICE IN THE CONTEXT OF MANAGING A FRAIL ~~OLDER~~ ADULT IN THE COMMUNITY:

1. IT IS CRUCIAL THAT THE PROVIDERS OF CARE HAVE A WORKING KNOWLEDGE OF GERIATRICS AND THE CARE OF THOSE WITH

ALZHEIMER'S DISEASE AND RELATED DISORDERS. THESE PROVIDERS MUST BE ABLE TO PROVIDE DEMENTIA CAPABLE SERVICES WHICH INCLUDE SUBSTANTIAL SUPPORT AND KNOWLEDGE IN THE AREA OF CAREGIVER STRESS.

2. THE PLAN OF CARE IS CONSUMER DRIVEN AND THE DECISION-MAKING PROCESS INCLUDES THE INDIVIDUAL AND/OR RESPONSIBLE PARTY.
3. THE MANAGEMENT BE COORDINATED THROUGH AN INTERDISCIPLINARY TEAM OF PROFESSIONALS, PARA PROFESSIONALS, FAMILY MEMBERS AND/OR RESPONSIBLE PARTIES.

THE FOLLOWING REPRESENT OBSTACLES TO OBTAINING SERVICES:

1. SECURING PAYMENT FOR SERVICES IN OUR CURRENT SYSTEM FOR SOMEONE WHO NEEDS ONGOING "CUSTODIAL CARE" IS ALMOST IMPOSSIBLE. THE ISSUE OF NEEDING SKILLED CARE SUCH AS: REGISTERED NURSES, HOME HEALTH AIDES, PHYSICAL THERAPY, AND OCCUPATIONAL THERAPY VERSUS CUSTODIAL CARE SUCH AS COMPANIONS, HOME MAKERS, OR DAY CARE IS A SIGNIFICANT PROBLEM FOR PEOPLE SUFFERING FROM ALZHEIMER'S DISEASE. AN INDIVIDUAL WITH ALZHEIMER'S DISEASE COULD BE MANAGED IN A MUCH MORE COST EFFECTIVE MANNER IF THE SYSTEM WAS DESIGNED AS A COMBINATION OF A MEDICAL AND SOCIAL MODEL OF CARE.
2. PROVIDERS OF CARE ARE NOT TRAINED IN PROVIDING THE APPROPRIATE LEVEL OF CARE, ESPECIALLY IN THE AREA OF DEMENTIA CARE.
3. THE LACK OF A COORDINATED SERVICE DELIVERY SYSTEM FOSTERS THE CURRENT EXPENSIVE AND COMPLEX SYSTEM OF LONG TERM CARE.

MY RECOMMENDATIONS REGARDING MANAGED CARE MODELS FOR FRAIL ELDERS INCLUDE:

1. MANAGED CARE MODELS MUST RECOGNIZE THAT THE OLDER ADULT AND HIS OR HER INFORMAL SUPPORT NETWORK OF FAMILY AND FRIENDS ARE THE CENTRAL FOCUS OF THE PLAN OF CARE.
2. MANAGED CARE MODELS MUST PROVIDE QUALITY SERVICES WHICH RESPOND SPECIFICALLY TO THE NEEDS OF FRAIL ELDERS. WHILE THE "HIGH TECH" INTERVENTIONS OF THE LAST DECADES RESPOND TO THE NEEDS OF SOME POPULATIONS, SERVICES FOR ELDERS MUST INCLUDE "LOW TECH-HIGH TOUCH" SERVICES SUCH AS: HOMEMAKER, COMPANION AND HOME DELIVERED MEALS.
3. MANAGED CARE ORGANIZATIONS MUST UTILIZE A COMPREHENSIVE CARE MANAGEMENT MODEL IN ORDER TO IDENTIFY THE UNIQUE STRENGTHS AND DEFICITS IN EACH CLINICAL SITUATION, AND TO MAXIMIZE ALL AVAILABLE COMMUNITY RESOURCE OPTIONS.
4. MANAGED CARE MODELS MUST PROVIDE APPROPRIATE ACCESS TO SPECIALTY CARE WHEN NECESSARY. IN VIEW OF THE INCREASING PREVALENCE OF ALZHEIMER'S DISEASE AND RELATED DISORDERS, IT IS IMPERATIVE THAT THE SERVICES OF GERIATRICIANS, GERIATRIC PSYCHIATRISTS, NEUROLOGISTS, NURSES AND SOCIAL WORKERS BE AVAILABLE TO ADDRESS THE NEEDS OF THESE ELDERS AND THEIR CAREGIVING FAMILIES.
5. SPECIAL ATTENTION MUST BE PAID TO THE ROLE OF RESPITE CARE SERVICES FOR INFORMAL CARE PROVIDERS. IT IS NATIONALLY RECOGNIZED ~~THAT~~ A FULL 80% OF ALL CARE TO FRAIL ELDERS IS PROVIDED BY THEIR INFORMAL CARE SYSTEMS; SPOUSES, CHILDREN, GRANDCHILDREN, AS WELL AS SIGNIFICANT FRIENDS AND NEIGHBORS.

WITHOUT ADEQUATE RESPITE CARE, INFORMAL CAREGIVERS ARE UNABLE TO CONTINUE THEIR VITAL ROLE IN THE LONG TERM CARE SYSTEM.

6. MANAGED CARE MODELS MUST ADDRESS THE CURRENT INSTITUTIONAL BIAS IN THE LONG TERM CARE SYSTEM, RECOGNIZING THE DESIRE OF THE ELDERLY TO REMAIN IN THE COMMUNITY, TO REMAIN IN THEIR OWN HOME WHENEVER POSSIBLE, MANAGED CARE MODELS MUST INCLUDE A FULL RANGE OF COMMUNITY CARE SERVICES IN THEIR BENEFIT PLANS.

THANK YOU FOR YOUR ATTENTION.

ALZHEIMER'S®
ASSOCIATION
Someone to Stand by You

MEDICAID MANAGED CARE FOR
THE ELDERLY AND OTHERS WITH SPECIAL NEEDS
June 24, 1997

THE FOLLOWING REPRESENT THE BEST PRACTICE IN THE CONTEXT OF MANAGING A FRAIL OLDER ADULT IN THE COMMUNITY:

◆1. IT IS CRUCIAL THAT THE PROVIDERS OF CARE HAVE A WORKING KNOWLEDGE OF GERIATRICS AND THE CARE OF THOSE WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS. THESE PROVIDERS MUST BE ABLE TO PROVIDE DEMENTIA CAPABLE SERVICES WHICH INCLUDE SUBSTANTIAL SUPPORT AND KNOWLEDGE IN THE AREA OF CAREGIVER STRESS.

◆2. THE PLAN OF CARE IS CONSUMER DRIVEN AND THE DECISION-MAKING PROCESS INCLUDES THE INDIVIDUAL AND/OR RESPONSIBLE PARTY.

◆3. THE MANAGEMENT BE COORDINATED THROUGH AN INTERDISCIPLINARY TEAM OF PROFESSIONALS, PARA PROFESSIONALS, FAMILY MEMBERS AND/OR RESPONSIBLE PARTIES.

THE FOLLOWING REPRESENT OBSTACLES TO OBTAINING SERVICES:

◆1. SECURING PAYMENT FOR SERVICES IN OUR CURRENT SYSTEM FOR SOMEONE WHO NEEDS ONGOING "CUSTODIAL CARE" IS ALMOST IMPOSSIBLE. THE ISSUE OF NEEDING SKILLED CARE SUCH AS: REGISTERED NURSES, HOME HEALTH AIDES, PHYSICAL THERAPY, AND OCCUPATIONAL THERAPY VERSUS CUSTODIAL CARE SUCH AS COMPANIONS, HOME MAKERS, OR DAY CARE IS A SIGNIFICANT

PROBLEM FOR PEOPLE SUFFERING FROM ALZHEIMER'S DISEASE. AN INDIVIDUAL WITH ALZHEIMER'S DISEASE COULD BE MANAGED IN A MUCH MORE COST EFFECTIVE MANNER IF THE SYSTEM WAS DESIGNED AS A COMBINATION OF A MEDICAL AND SOCIAL MODEL OF CARE.

- 2. PROVIDERS OF CARE ARE NOT TRAINED IN PROVIDING THE APPROPRIATE LEVEL OF CARE, ESPECIALLY IN THE AREA OF DEMENTIA CARE.
- 3. THE LACK OF A COORDINATED SERVICE DELIVERY SYSTEM FOSTERS THE CURRENT EXPENSIVE AND COMPLEX SYSTEM OF LONG TERM CARE.

MY RECOMMENDATIONS REGARDING MANAGED CARE MODELS FOR FRAIL ELDERS INCLUDE:

- 1. MANAGED CARE MODELS MUST RECOGNIZE THAT THE OLDER ADULT AND HIS OR HER INFORMAL SUPPORT NETWORK OF FAMILY AND FRIENDS ARE THE CENTRAL FOCUS OF THE PLAN OF CARE.
- 2. MANAGED CARE MODELS MUST PROVIDE QUALITY SERVICES WHICH RESPOND SPECIFICALLY TO THE NEEDS OF FRAIL ELDERS. WHILE THE "HIGH TECH" INTERVENTIONS OF THE LAST DECADES RESPOND TO THE NEEDS OF SOME POPULATIONS, SERVICES FOR ELDERS MUST INCLUDE "LOW TECH-HIGH TOUCH" SERVICES SUCH AS: HOMEMAKER, COMPANION AND HOME DELIVERED MEALS.
- 3. MANAGED CARE ORGANIZATIONS MUST UTILIZE A COMPREHENSIVE CARE MANAGEMENT MODEL IN ORDER TO IDENTIFY THE UNIQUE STRENGTHS AND DEFICITS IN EACH CLINICAL SITUATION, AND TO MAXIMIZE ALL AVAILABLE COMMUNITY RESOURCE OPTIONS.

◆4. MANAGED CARE MODELS MUST PROVIDE APPROPRIATE ACCESS TO SPECIALTY CARE WHEN NECESSARY. IN VIEW OF THE INCREASING PREVALENCE OF ALZHEIMER'S DISEASE AND RELATED DISORDERS, IT IS IMPERATIVE THAT THE SERVICES OF GERIATRICIANS, GERIATRIC PSYCHIATRISTS, NEUROLOGISTS, NURSES AND SOCIAL WORKERS BE AVAILABLE TO ADDRESS THE NEEDS OF THESE ELDERS AND THEIR CAREGIVING FAMILIES.

◆5. SPECIAL ATTENTION MUST BE PAID TO THE ROLE OF RESPITE CARE SERVICES FOR INFORMAL CARE PROVIDERS. IT IS NATIONALLY RECOGNIZED THAT A FULL 80% OF ALL CARE TO FRAIL ELDERS IS PROVIDED BY THEIR INFORMAL CARE SYSTEMS; SPOUSES, CHILDREN, GRANDCHILDREN, AS WELL AS SIGNIFICANT FRIENDS AND NEIGHBORS. WITHOUT ADEQUATE RESPITE CARE, INFORMAL CAREGIVERS ARE UNABLE TO CONTINUE THEIR VITAL ROLE IN THE LONG TERM CARE SYSTEM.

◆6. MANAGED CARE MODELS MUST ADDRESS THE CURRENT INSTITUTIONAL BIAS IN THE LONG TERM CARE SYSTEM, RECOGNIZING THE DESIRE OF THE ELDERLY TO REMAIN IN THE COMMUNITY, TO REMAIN IN THEIR OWN HOME WHENEVER POSSIBLE, MANAGED CARE MODELS MUST INCLUDE A FULL RANGE OF COMMUNITY CARE SERVICES IN THEIR BENEFIT PLANS.

Ms. CHRISTENSEN. Thank you.

Don.

STATEMENT OF DONALD MINOR, CLIENT ADVOCATE, CARE MARK, ON BEHALF OF THE NATIONAL ASSOCIATION OF PEOPLE WITH AIDS, WASHINGTON, DC

Mr. MINOR. Thank you, Mr. Chairman, for the invitation to speak with you on this issue and for the opportunity to address the special health care needs of people living with HIV and other catastrophic disorders.

My name is Donald Minor. I am a person living with HIV and hemophilia. I am speaking with you today on behalf of the National Association of People with AIDS. NAPWA is an organization dedicated to serving as both a national information resource and voice for the needs and concerns of people living with HIV throughout the United States.

As you may know, HIV disease is a disorder which leads to a progressive weakening or destruction of the immune system. Once it has crippled the immune system, the body becomes open to a host of opportunistic infections. HIV/AIDS has remained a pandemic since the first diagnosed cases in 1981 and remains a tremendous national crisis. While our Nation's newspapers report the marvel of new treatments and the death rate from this disease declining, let us be warned that this crisis it not over yet.

I have met with people from every State of the Nation living with HIV, from every economic status, race, gender, and progression of the disease. AIDS does not discriminate. It affects babies, children, adolescents, teenagers, young adults, parents, grandparents, and senior citizens.

I come to you from Johnson City, TN. They call me "the redneck from Tennessee." I was born with hemophilia. Hemophilia is a blood-clotting disorder that affects over 20,000 individuals in the United States. Via a contaminated factor replacement product, I contracted the HIV virus in 1983. This was confirmed in 1985 when the first tests were available to detect the virus.

Having hemophilia already created a problem in getting insurance. I lost coverage as fast as I could get it. I either maxed out the policy, or it was denied due to preexisting conditions. I managed to be placed on a catastrophic insurance pool with high premiums and many limiting conditions.

Soon after I was diagnosed HIV-positive, I lost my job. I applied for disability, but the judge denied it due to my education. He stated that I could still find a job. From there, the nightmare started. No job, no prospects, no disability, and very low self-esteem.

That is when I got mad and fought back. I became involved in my own advocacy and became a willing person to speak for others. It has been a long, hard road to this day.

Today I participate in a State managed care program called TennCare. When it started, it was a nightmare for those of us with catastrophic disease. There were literally life and death scenarios, because TennCare was implemented without adequate planning. I can personally tell you what managed care is when it has no rules, no boundaries, and no standards of care that are measurable with outcomes tools. I have been denied medications, had medications delayed, creating health risks, discharged from the hospital before my doctor was ready for me to go home and told I could not see my AIDS and hemophilia specialist until a primary care physician could work me in—in about 3 months. Simply stated, getting meds late for me could mean death. Not getting the right meds in the right combination could and did result in health complications.

TennCare is now a viable health program, but it still needs improvement when it comes to dealing with catastrophic diseases like HIV and AIDS. I can tell you from personal experience that improper disease state management costs everyone—you the taxpayer, the managed care organization, and those of us who are living with these diseases. I have almost died, not from HIV, but from improper disease management. One particular protease inhibit drug is great for many HIV-positive people, but for me, will make me spontaneously bleed internally.

As our Nation transitions our public health care programs into a new era of cost containment and reduction in services, we must take a strong look at how these new programs affect care of persons living with catastrophic diseases. What process helps these persons stay viable and productive individuals in their communities?

Medicaid in particular forms the bedrock of our Nation's response to caring for people living with HIV. In many States, Medicaid has changed into a managed care program, either through a demonstration project or a fully operational program. The Health Care Financing Administration estimates that 90 percent of children with HIV depend on Medicaid, and 50 percent of adults with AIDS or advanced HIV also rely on Medicaid. Medicare is the next largest resource for these people. With people living longer, Medicare is becoming an even more important program for people living with HIV.

I must tell you that the Ryan White Comprehensive AIDS Resources Emergency Act or CARE Act is greatly depended on. This Act has been a life-saver for many. This program provides supplemental relief to fill in the service gaps left unfilled by Medicaid, Medicare and other programs. It acts as the payer of last resort. Still, there are many people with HIV who lack regular access to health care. Just in the last several weeks, several State ADAP programs have run out of funds, meaning there will be no HIV medications for many in this country.

No preventive treatments such as protease inhibitors starts a chain reaction. Simply stated, no treatments leads to opportunistic infections, opportunistic infections lead to higher-cost treatments, provided by public health and community-based organizations.

I just mentioned protease inhibitors, a new class of drugs made available in the last year and a half. These new drug treatments have given a new lease on life for many, including me. This advance allows us to attack the virus on a different front than the older medications such as AZT. Taken in combination with these other classes of antivirals, this virus has been attacked and limited to undetectable levels in many.

Please do not let this mislead you. While this has been a tremendous breakthrough for HIV treatment, it is not a cure. There is not enough history of this treatment to give us absolute evidence that it will eradicate the virus. Many cannot take these medications. Many of these medications have severe side effects. Many cannot afford these medications or are denied them for various reasons. These medications can average close to $15,000 per year plus. I average taking $3,700 worth of medications per month, not counting my hemophilia medication.

I am not speaking to you as a committed managed care foe. I believe managed care can work. But everybody needs to be on the same page when it comes to disease state management. For every obstacle to quality care with optimum outcomes, there is a solution. From our perspective, I would like to recommend three elements as part of the solution.

First, there must be an assurance that gatekeepers, case managers, utilization review officials and others who approve or disapprove claims must become knowledgeable about HIV and other catastrophic disorders. Managed care needs to protect consumers by making sure that payers demonstrate expertise in disease management and are held accountable for providing high-quality care.

Those of us who have been fortunate enough to be treated in a comprehensive hemophilia center can testify to the improved outcomes generated by those trained in the management of hemophilia.

Second, there must be a Federal role in setting certain standards and creating expectations for specific outcomes. At present, every HMO is different, every State is different, and managed care plans set their own rules on a daily basis.

I also believe that the Federal Government must support efforts to risk-adjust capitated payments that managed care organizations use to control their costs. There must be incentives for quality care instead of incentives to just do it the cheapest way or where the best profit is. Most of the time, managed care sees the cost today but not the cost tomorrow.

Third, a great amount of interest exists in the HIV community for exploring ways to expand Medicaid coverage to people living with HIV, but who are not yet disabled by AIDS. Incomplete data suggest that this could be done in a cost-neutral manner, because individuals could be given such drugs as protease inhibitors and other treatments that could prevent them from progressing to full-blown AIDS. Finding ways for the Federal Government, State governments and managed care organizations to expand coverage and improve outcomes for persons living with HIV and other disorders is the right thing to do.

I wish I had more time to discuss with you all that I have dealt with, witnessed, discovered and been educated about as a catastrophic disease advocate. By your invitation, I will be happy to communicate with you on this issue in our Nation's health care system.

I very much appreciate the opportunity to address this respected body, and I would be pleased to answer any questions that you may have.

Thank you.

[The prepared statement of Donald Minor follows:]

Testimony by Donald Minor

Before

The Special Committee on Aging
United States Senate

Tuesday, June 24, 1997

NAPWA

NATIONAL
ASSOCIATION
OF PEOPLE
WITH AIDS

Thank you Mr. Chairman, for the invitation to speak with you on this issue and for the opportunity to address the special health care needs of people living with HIV and other catastrophic disorders. My name is Donald Minor. I am a person living with HIV and Hemophilia. I am speaking with you today on behalf of the National Association of People with AIDS. NAPWA will submit written testimony for the record.

NAPWA is an organization dedicated to serving as both a national information resource and a voice for the needs and concerns of people living with HIV throughout the United States.

As you may know HIV disease is a disorder that leads to a progressive weakening or destruction of the immune system. Once it has crippled the immune system the body becomes open to a host of opportunistic infections. HIV/AIDS has remained a pandemic since the first diagnosed cases in 1981 and remains a tremendous national crisis. While our nations's newspapers report the marvel of new treatments and the death rate declining from this disease, let us be warned that this crisis is not over yet.

I have met people from every state of the nation living with HIV, from every economic status, race, gender and progression of the disease. AIDS does not discriminate. It affects babies, children, adolescents, teenagers, young adults, parents, grandparents, and senior citizens.

I come to you from Johnson City, TN. I was born with Hemophilia. Hemophilia is a blood clotting disorder that affects over 20,000 individuals in the United States. Via a contaminated factor replacement product, I contracted the HIV virus in 1983. This was confirmed in 1985 when the first tests were available to detect the virus.

Having Hemophilia already created a problem in getting insurance. I lost coverage as fast as I could get it. I either maxed out the policy or it was denied due to preexisting conditions. I managed to be placed on a catastrophic insurance pool with high premiums and many limiting conditions. Soon after I was diagnosed HIV positive, I lost my job. I applied for disability, but the judge denied it due to my education. He stated, I could still find a job. From there the nightmare started. No job, no prospects, no disability and low self-esteem. That's when I got mad and fought back. I became involved in my own advocacy and became a willing person to speak for others. It has been a long hard road to this day.

1413 K Street, N.W.,
Washington D.C. 20005
Phone: (202) 898-0414
FAX: (202) 898-0435

Today I participate in a state managed care program called Tenncare. When it started, it was a nightmare for those of us with catastrophic disease. There were literally life and death scenarios because TennCare was implemented without adequate planning. I can personally tell you what managed care is when it has no rules, no boundaries and no standards of care that are measurable with outcomes tools. I have been denied medications, had medications delayed - creating health risks, discharged from the hospital before my doctor was ready for me to go home and told I could not see my AIDS and Hemophilia specialist until a primary care physician could work me in - in about three months. Simply stated, getting meds late, for me, could mean death. Not getting the right meds in the right combinations could and did result in health complications.

Tenncare is now a viable program, but it still needs improvement when it comes to dealing with catastrophic diseases like HIV/AIDS. I can tell you from personal experience that improper disease state management costs everyone - you the taxpayer, the managed care organization and those of us who are living with these diseases. I have almost died, not from HIV but from improper disease management. One particular protease inhibitor drug is great for many HIV positive people, but for me will make me spontaneously bleed internally.

As our nation transitions our public health care programs into a new era of cost containment and reduction in services, we must take a strong look at how these new programs affects care of persons living with catastrophic disease. What process helps these persons stay viable and productive individuals in their community. Medicaid, in particular, forms the bedrock of our nation's response to caring for people living with HIV. In many states, Medicaid has changed into a managed care program, either through a demonstration or a fully operational program. The Health Care Financing Administration estimates that ninety percent of children with HIV depend on Medicaid, and fifty percent of adults with AIDS, or advanced HIV, also rely on Medicaid. Medicare is the next largest resource. With people living longer, Medicare is becoming an even more important program for people living with HIV.

I must tell you that the Ryan White Comprehensive AIDS Resources Emergency Act or CARE Act is greatly depended on. This Act has been a life saver for many. This program provides supplemental relief to fill in the service gaps left unfilled by Medicaid, Medicare and other programs--it acts as a payor of last resort. Still, there are many people with HIV who lack regular access to health care. Just in the last several weeks, several state ADAP programs have run out of funds. Meaning, there will be no HIV treatment medications for many in this country.

No preventive treatments, such as protease inhibitors, starts a chain reaction. Simply stated, no treatments lead to opportunistic infections. Opportunistic infections lead to higher cost treatments, provided by public health and community based organizations.

I just mentioned protease inhibitors, a new class of drugs made available in the last year and a half. These new drug treatments have given a new lease on life for many, including me. This advance allows us to attack the virus on a different front than the older medications, such as AZT. Taken in combination with these other classes of antivirals, the virus has been attacked and limited to undetectable levels in many. Please do not let this mislead you. While this has been a tremendous breakthrough for HIV treatment, it is not a cure. There is not enough history of this treatment to give us absolute evidence that it will eradicate the virus. Many cannot take these medications. Many of these medications have severe side-effects. Many cannot afford these medications or are denied them for various reasons. These medications can average close to $15,000 per year plus. I average taking $3,700 per month, not counting my hemophilia medication.

I am not speaking to you as a committed managed care foe. I believe managed care can work. But, everybody needs to be on the same page when it comes to disease state management. For every obstacle to quality care with optimum outcomes, there is a solution. From our perspective, I would like to recommend three elements as part of the solution.

First, there must be an assurance that gatekeepers, case managers, utilization review officials, and others who approve or disapprove claims must become knowledgeable HIV. Managed care needs to protect consumers by making sure that payers demonstrate expertise in disease management and are held accountable for providing high quality care.

Those of us who have been fortunate to be treated in a comprehensive hemophilia center can testify to the improved outcomes generated by those trained the management of hemophilia.

Second, there must be a federal role in setting certain standards and creating expectations for specific outcomes. At present, every HMO is different, every state is different, and managed care plans set their own rules on a daily basis.

I also believe that the federal government must support efforts to risk adjust capitated payments that managed care organizations use to control their costs. There must be incentives for quality care instead of incentives to just do it the cheapest way or where the best profit is. Most of the time, managed care sees the cost today, but not the cost tomorrow.

Third, a great amount of interest exists in the HIV community for exploring ways to expand Medicaid coverage to people living with HIV, but who are not yet disabled by AIDS. Incomplete data suggest that this could be done in a cost neutral manner because individuals could be given protease inhibitors and other treatments that could prevent them from progressing to AIDS. Finding ways for the federal government, state governments and managed care organizations to expand coverage and improve outcomes for persons living with HIV and other disorders is the right thing to do.

I wish that I had more time to discuss with you all that I have dealt with, witnessed, discovered, and have been educated about as a catastrophic disease advocate. By your invitation, I will be happy to communicate with you on this issue in our nation's health care system.

I very much appreciate the opportunity to address this respected body. I would be pleased to answer any questions that you may have.

Ms. CHRISTENSEN. Thank you. [Inaudible comments.]

DISCUSSION

Ms. CHRISTENSEN. If people would write their questions out, I think it would save time and [inaudible]

Ms. MCGINLEY. Can I say something? Does anybody here work for any Members from Pennsylvania? [No response.]

No. OK. I just happened to have something specific to the State of Pennsylvania which I would share with people.

Mr. YOUNG. At CCD, the Consortium for Citizens with Disabilities, we have a Web page, and we are going to be putting this information up on the Web page, too; so if anybody needs to get it in electronic format, I put my e-mail address on the cover of my statement, and you can either get the Web address from me—or, Kathy, did you bring it——

Ms. MCGINLEY. Actually, we have it.

Mr. YOUNG. OK.

Ms. CHRISTENSEN. Tony, is your statement on the table?

Mr. YOUNG. Yes, it is over there.

Ms. MCGINLEY. Here is the Web address. www.radix.net/~ccd. That will give the general page. This testimony will be posted on the Health Task Force page—with other information that would be helpful, too.

Ms. CHRISTENSEN. Questions, comments?

QUESTION. I have a question for Donald Minor. [Inaudible.]

Mr. MINOR. I believe she was wanting to know, at the beginning of the implementation of TennCare in the State of Tennessee, what were the major problems as far as catastrophic disease was concerned, and then what has helped it improve to this point.

First of all, let me say this carefully, because other States are looking at TennCare, and I am very alarmed at them copying the same program. No. 1, TennCare was implemented by putting the buggy before the horse. Very simply stated, they enacted a program without input from physicians who were specialists, and in many instances, they did not have because they had no physician enrolled in TennCare at that particular hospital. He went to four counties before he was treated, and it took me threatening the Governor with putting him on the front page in the morning, and he made the telephone call to get that patient treated. So we have been through that, and we are still going through some of those scenarios today.

I met with Blue Cross/Blue Shield 2 weeks ago, talking about the same problem with primary care physicians. If you are familiar with the gatekeeper role, in order to get specialty care, you have got to go to the primary care physician first and physically be referred to that specialist. Well, if you are a primary care physician and all of a sudden, overnight, they give you 1,700 patients, and you have no earthly idea what disease states they have, and you call in for an appointment, and they say, "Well, the first appointment I can give you is 3 months from now," you are looking at people who are panicking overnight who have got to have medication such as Factor 8 for hemophilia or protease inhibitors that you cannot miss a day taking who are not able to get in to see a primary care physician and be referred. This has got to be addressed for not just these two disease states, but many of the others.

Does that answer your question?

QUESTION. Yes. I was particularly interested in TennCare and what the improvement has been.

Mr. MINOR. The improvement has been because many of the major HMOs that are involved, which are 12 in TennCare, are now starting to realize that they are having problems dealing with catastrophic disease, that the capitation rate is not enough to take care of these disease states, and it has already bankrupted three of those HMOs on catastrophic diseases. So they are coming back to the TennCare roundtable and saying, We need to re-talk this.

So the recommendation is to leave catastrophic disease out of a new demonstration project until you have all the bugs worked out, and then roll in your catastrophic disease to where you have the right skills and the right training to manage it.

Ms. MCGINLEY. May I add something, too? We have 1,200 State and local chapters, and they try in their States to play a role when States are working on these managed care waivers or plans. One of the major concerns in a lot of States—and I can give specific States if people are interested—is the fact that even though advocates are at the table, and they are part of the working group that is supposedly developing the plan, often, when the plan is ready to go to HCFA or whomever for approval, the concerns of the consumers have not really been reflected or included in the plan, and neither has the expertise of the consumers been included in the plan. That is a major problem.

Mr. GUIDA. I should say in follow-up—and I agree with Mr. Minor—the net improvement of TennCare is that there are now 200,000 or 300,000 low-income Tennesseans who did not have access to health insurance before TennCare who do now. The savings produced by TennCare, these reductions in managed care into the Medicaid program, were sufficient to expand health coverage to a significant number of Tennesseans who did not have access to health insurance prior to the program. That's the net—that's the most significant improvement produced by the program.

The effects of the program on specific disability groups have been variable, and I don't mean to editorialize. The mental health managed care program in Tennessee is a disaster.

Mr. MINOR. Amen.

Mr. GUIDA. It is chaotic. The State attempted to carve out—meaning establish a special managed care program—for adults with severe mental illness and children with serious emotional disturbances. The capitation rate, the amount of money that the State agreed to pay to the HMOs that ran that carve-out program and then in turn the subcapitation rate, or the amount of money that the HMOs paid to the community providers, is so low that the community mental health centers—there are only six community mental health centers in the entire State of Tennessee—one of them is in bankruptcy in Memphis, and another is close to bankruptcy. There is a confidential HCFA site visit report which indicates that part of the problem is that the HMOs that run the mental health carve-out own private psychiatric facilities in the State of Tennessee and are shuttling consumers to those inpatient hospitals rather than to community-based services, which is why the community mental health centers in addition to the subcapitation rate, which is very low, are in a state of financial crisis.

You have situations in Philadelphia where an individual in a state of psychiatric crisis is referred to a psychiatric emergency room, and that emergency facility will refuse to provide service because it is not under contract with the HMO that participates in the public sector carve-out program.

That is one of the consequences of what we are talking about here. So as I said, the effects are variable, depending upon the disability population.

QUESTION. I have a question for any of the panelists. Who are the individuals and/or groups who are opposed to exempting persons with special needs under Medicaid managed care, and what are the arguments for opposing that?

Mr. MINOR. From my point of view, I do not see anybody who is wanting to exempt anybody from managed care rolls in the States. They are just wanting to make sure that they get a good grasp on disease state management before they roll these people into managed care programs and are not adequately able to take care of them.

Ms. MCGINLEY. The CCD Health Task Force and other disability groups here have been supportive of a provision within Senator Chafee's bill which would have exempted individuals with disabilities from mandated Medicaid managed care, and unfortunately, that was not included in the Finance Committee bill.

Fortunately, Senator Grassley came up with an amendment to set up the guidelines that Al talked about. The opposition that I think would be—and I do not know—I am just saying that I would think most of the opposition would come from States and Governors who would like to have the flexibility to do this.

There is a GAO report, which I think you have copies of out there, which was done last year. It shows how Medicaid managed care serving the disabled challenges State programs. One of the concerns for the disability community is the fact that the States do not have the experience, they do not have the infrastructure, they do not have the physicians, they do not have the physicians and the other services in place, and to push people into that right now is going to be very damaging.

Mr. YOUNG. Well, it's not managed care per se that we are opposed to. It is poor managed care; it's a lack of choice in managed care; it's a lack of rights and quality that we see that people have been forced into in managed care.

We feel that managed care is the wave of the future. It is an appropriate way to get good service, and particularly preventive service. I think the big misnomer now is that we have a health insurance system. We don't—we have a sickness insurance system—you buy insurance against the fact that you may get sick someday, and it doesn't cover a lot of the preventive services and the things that would keep you from getting sick. Managed care has the potential to do that, and to bring all those services, medical care and support services that people with disabilities need together in one place in a coordinated matter that is both cost-effective and very efficient.

But unless we get the choice and the consumer protections and the quality and the outcomes that are promised by managed care, then all you've got is another track for people with disabilities to go into and die and disappear.

QUESTION. [Inaudible.] I was wondering what you hope to get out of today's meeting.

Mr. YOUNG. We wanted to respond to a request from a friend on the Aging Committee and educate as many folks as we could about our concerns about managed care and to move the process along to a quality managed care system as quickly as possible.

Ms. LEONARD. I know one of our thoughts was to clearly demonstrate the need for knowledge of each of the diseases. I think the common theme across the table is really knowing what it means to have Alzheimer's disease, what it means to have a mental illness—your point about the individual with schizophrenia—and all the other illnesses that are profiled here.

Probably the most frustrating thing—and I make it a point to continue being "in the trenches." I am a firm believer as a clinician and as someone who is very interested in public policy, that I need to eat, sleep and drink the realities of what happens in Washington and in Hartford—and part of my frustration and many of my colleagues is that many decisions are made without the knowledge of what it really means to have the disease. So if I may speak for myself and the association, it is to communicate to each and every one of you that there are people with special needs, and as Susan so eloquently stated, even within the special needs, there are special needs.

QUESTION. [Inaudible] and in an effort to make [inaudible] to bring a great deal of attention to that.

Ms. CHRISTENSEN. Laying the background for additional forums which will be more policy-oriented than this, describing who are we talking about.

Mr. MINOR. I simply want to stress two words, and those are "outcomes" and "accountability." It is extremely important—even though I speak for people with AIDS and people with hemophilia, I also deal with almost 15 other inherited genetic disorders, and I can tell you very strongly that we have not educated people about outcomes monitoring, and it is a simple tool that lets you know that you are doing the right things with the best outcomes.

I will make a statement quickly, that the new outcomes to, I think it is called H-E-D-I-S, HEDIS, I have real concerns with because it does not cover a lot of things that deal with catastrophic disease. If you are going to have an outcomes tool, it has got to be designed with that in mind, because if you don't know what the benefit is going to be, how do you know the plan? It is very simple—if you do not understand the outcomes of mental illness or Alzheimer's or cerebral palsy or whatever, when those things are not managed properly, then you have no concept of where the spending is. I emphasize that we look at tunnel vision, seeing that, hey, this is going to cost us "x" number of dollars today.

An example is for hemophilia, if a patient with hemophilia does not get Factor on time, it is not just the fact that he did not get his medicine on time—he now has permanent joint destruction; he now has to start looking at things like radial synovectomies at $30,000, total joint replacement at $100,000.

If you are a payer, an insurance group or an HMO, it baffles me why they do not understand—which would you rather pay, $1,200 for the Factor or $100,000 for a total joint replacement? Unfortunately, we are having difficulty getting people to see that simple little example, because they are too worried about what it's going to cost them today.

TennCare gives an HMO $1,260 to take care of somebody for a whole year. Folks, in 1 month, in July, I used $47,000 worth of medicine. Are you going to manage me with $1,260? Let me tell you—the reality is that my HIV doc gets paid $8 to see me. His answer to me is. Don, I'd rather take care of you free, because it costs me $150 to get the $8 reimbursed.

Do you think they want to manage these States such as our for $8? Folks, it just can't be done. So I have to applaud—there are a lot of dedicated people out there who are taking care of a lot of these disease states, and they are not getting the credit because they weren't even asked for their input in the beginning.

I emphasize what she said—we have got to be heard. We can't just sit at the table and say: Gee, whiz, we had somebody from Alzheimer's, and we had somebody here from cerebral palsy and mental health. You have got to hear what we're saying, because in the long run, the taxpayer is the loser, the Federal Government is the loser, the State government is the loser, and most important of all, the people we are trying to take care of are the losers.

Ms. CHRISTENSEN. Anybody else? [No response.]

Thank you all for coming.

I want to point out that we have three more forums in this room. July 8, we're looking at the managed care industry and their ability to serve people with special needs. We'll have a representative from GAO and a researcher, and we're hoping to get somebody from an HMO.

On July 15, we are going to look at quality and outcome measures; and on July 22, we'll have a panel discussing the State contracting process and the problems they face between contracting for Medicaid managed care.

Thank you all for coming. We really appreciate your attention.

[Whereupon the forum was concluded.]

THE STATE OF THE INDUSTRY

JULY 8, 1997

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The forum met, pursuant to notice, at 9:30 a.m., in the Dirksen Senate Office Building. Ms. Susan Christensen, Public Policy Fellow, presiding.

OPENING STATEMENT OF MS. SUSAN CHRISTENSEN

Ms. CHRISTENSEN. Good morning. I'm glad you were able to come this morning.

I am Susan Christensen, and I am a Public Policy Fellow with the Aging Committee Staff, Senator Grassley's staff. Also here today is Ken Cohen from Senator Breaux's staff, and I think some other folks are here. Is anybody else here from the Committee? [No response.]

OK. This is the second in a series of four forums on managed care for people with special needs. If you were here for the first forum on June 24, you heard that the Committee's interest in this topic greatly increased following a hearing we conducted on individuals with chronic conditions who were dually eligible for Medicaid and Medicare.

We discovered that many studies and anecdotal evidence revealed significant issues that still need to be resolved when serving people with special needs under a managed care plan. We divided those issues roughly into four main themes, which are the topics of our four forums.

At the first forum, we got a picture of what it means to be a person with special needs. Presenters described how health care needs to be delivered in certain ways for it to be effective, illustrating that people with chronic conditions don't just need more doctor or therapy visits; care must be individualized to the person's needs.

Today our theme is the ability of the current managed care industry to do just that—deliver health care effectively to individuals with a wide variety of specialized needs.

Our panelists will each do a short presentation, and then we will have time for questions and discussion, so please jot down any questions that come to mind as you listen. These folks are great sources of information, so we hope that you will take advantage of this opportunity.

There are two more forums after this. Next Tuesday, July 15, we will focus specifically on how managed care plans, or any health plan for that matter, can measure quality for a population that is so statistically small.

Finally, on Tuesday, July 22, we will have panelists discussing the problems faced by States that want to contract to purchase managed care plans for their Medicaid beneficiaries with special needs. Each of these forums is at 9:30 in this room.

Our plan is to make a formal record of these forums that will be available to you from the Aging Committee when we are done. I want to thank LaVita Westbrook for organizing all these and keeping us on track. She has done a great job.

Now I'll introduce our panelists. Bill Scanlon is director of the Health Financing and Systems Issue Area at the U.S. General Accounting Office. He has been engaged in health services research since 1975. Before joining GAO in 1993, Dr. Scanlon was co-director of the Center for Health Policy Studies and an associate professor in the Department of Family Medicine at Georgetown University. His research is focused in particular on the Medicare and Medicaid programs, especially provider payment policies, and the provision and financing of long-term care services, which is especially important for this population we are talking about.

Barbara Smith is a senior research staff scientist at the Center for Health Policy Research at the George Washington University. She is a lawyer specializing in health law and health policy analysis. Her work focuses on health care financing and the Federal budgetary implications of health care financing reform and the restructuring of the health care delivery system. Some of you may be familiar with the Center for Health Policy Research's recent study on Medicaid managed care contracts by the States. Barbara was very much involved in that.

Patricia Riley is Vice President of Government Programs, Policy and Planning for Medica Health Plans at Allina Health System based in Minneapolis. Ms. Riley has over 20 years of professional experience in health and human services, most of which is concentrated in Government health programs, including Medicare and Medicaid. She is one of the developers of the Prepaid Medical Assistance Programs, or PMAP, in Minnesota. I am glad she could come and join us today.

I believe we'll just go in the order of Bill, Barbara, and Patsy, and I will go ahead and turn it over to Bill.

STATEMENT OF WILLIAM J. SCANLON, DIRECTOR OF HEALTH FINANCING AND SYSTEMS ISSUE AREA, U.S. GENERAL ACCOUNTING OFFICE, WASHINGTON, DC

Mr. SCANLON. Thanks very much, Susan. I am very happy to be here today as the Aging Committee considers the important issue of managed care for people with disabilities, in particular people with very significant service needs.

I would like to start by talking some about what was presented at the panel 2 weeks ago, because I thought that their presentations provided a number of themes which are important to keep in mind as we consider the issues of managed care for people with special needs.

The panel 2 weeks ago demonstrated very vividly the broad range of service needs for people with severe, chronic and disabling conditions, people who may have a physical condition or diagnosis such as cerebral palsy, multiple sclerosis, spinal cord or traumatic brain injury, hemophilia, or AIDS; also, people with mental retardation, people with severe and persistent mental illness; and finally. Even though their conditions are covered by the above categories, the elderly stand out as a separate group, both because of the prevalence of these types of conditions among elderly individuals as well as the different financing arrangements available for elderly individuals.

The panel described very well the need for services, services involving the treatment of the conditions that these individuals had that included medical and nursing services, therapies, drugs, prostheses, durable medical equipment. They also talked about the services that related to the consequences of these conditions, consequences in particular with respect to the loss of functioning and that require an individual to need assistance with services like personal care, the maintenance of a household, or respite for family caregivers.

I wanted to make that distinction because it is a distinction that is not often made. There tends to be some confusion about the range of services and who is responsible for what.

We hear many times that the system of health care in this country is not well-suited for people with chronic illness, and that may be very well true in terms of both types of services. However, it is very frustrating to be engaged in a discussion or a debate when one party is talking about the services related to the treatment of a condition, and another party is talking about the services that are supposed to compensate for the loss of functioning that results from having a condition.

It is also an important distinction, I think, when we talk about the issue of managed care for persons with special needs, because we are often not asking, or generally not asking, the managed care organizations to assume responsibility for the services related to the loss of functioning; what we are asking them to do is assume responsibility for the services related to the treatment of the conditions that the individuals have.

One of the other strong themes coming out of that panel was the real complexity of needs on the part of medical and professional services that any one individual is going to need, let alone the whole population. An example was given of a boy with cerebral palsy who needed the services of a pediatrician, and preferably or most importantly, a pediatrician familiar with cerebral palsy, as well as a neurologist, a urologist, an orthopedic surgeon, physical therapist, occupational therapist, and speech therapist. A similar case was described of an individual having spina bifida who needed a neurologist, a hematologist, a gastroenterologist, a urologist and an internist to help manage all of those specialties that were providing services.

It was clear that access to specialists is important, but even more important, or a further distinction, access to subspecialists, specialists who are not just a neurologist, but a neurologist who specializes in the condition that an individual may have, and that there is research that indicates that it matters whether or not an individual is getting state-of-the-art treatment of his or her condition in terms of the outcomes that that individual may have.

The third theme that came out of that panel was that this care that individuals are going to require is care for a lifetime, and that they have been strongly influenced by their conditions, that their ability to work may have been compromised early in life—they may never have had a chance to work, and they probably are not going to have a chance to work in the future. Therefore, their economic resources are often limited.

In addition, when some of these conditions occur very early in life, their social resources are often limited. When you look at the population of people with special needs, they are much less likely than the rest of the population to have ever married, so they do not have a spouse or a family, who are often the most important caregivers for individuals with chronic conditions.

These people with special needs are a very important part of the Medicaid program. Currently, the people who are elderly or have a disability comprise about 28 percent of the Medicaid population, but they account for 61 percent of Medicaid expenditures, and that somewhat understates how expensive it is to care for individuals or provide care for individuals with special needs, because after all, there is a significant population of dual-eligibles, and Medicare is paying a significant share of the cost of the medical care for those individuals.

We have seen in recent years the movement to Medicaid managed care. It has been sort of an outgrowth of the rapid growth of Medicaid costs over the late 1980's and early 1990's and the belief that managed care provides some opportunity to bring those costs under better control.

In 1996, about 15 percent of the Medicaid beneficiaries were in capitated managed care plans; however, 90 percent of them were in the AFDC or AFDC-related categories. Only about 10 percent of them were in the disabled or elderly categories.

Last year, we undertook a review of State activities with respect to managed care for people with disabilities and the elderly and found out that there were 17 States that were significantly involved in providing services to these populations through managed care. In six of these States, there was mandatory enrollment of individuals in managed care, and only one of these had 3 years or more of experience when we did our review last year. The other programs in the other 11 States were all voluntary and still were relatively small, although there were about 12 States at that time that were planning to implement some type of mandatory enrollment for at least some of their disabled populations.

This review, as well as the discussions about the movement of persons with special needs into Medicaid managed care has raised questions about the readiness of States and the readiness of the plans to serve this population, given that historically, the bulk have been interested in managed care for a population of much healthier people—the moms and kids in the Medicaid program.

Therefore, one of the things that I think we need to focus on is what considerations we should keep in mind regarding the movement of people with special needs into managed care. Starting by looking at the managed care model, which involves the use of primary care physicians as gatekeepers to ensure that services are both appropriate and necessary, and to avoid the use of unnecessary specialty care, as well as the component of the managed care system where we pay managed care organizations with a capitated payment which provides an incentive to both limit services and creates concerns about under-service.

We need to understand what kinds of implications these two principal features of managed care have for populations with special needs. One of the things that came out of the panel 2 weeks ago was that the primary care model may not be the best model for persons with special needs, and it suggested that there are at least four areas that we need to address as we think about moving individuals with special needs into managed care arrangements.

First of all, we need to ensure that there is an appropriate provider network established for such individuals. Second, we need to ensure that the rates being paid to plans are set accurately, to both fairly compensate the plan and reduce the undesirable incentives to inappropriately service individuals. Third, we need to come to an agreement on what should be the scope of coverage, given that the services needed by such individuals may extend beyond what the managed care organization is going to provide. Finally, we need to know how we can hold plans accountable for ensuring that the individuals that have been assigned to them are receiving appropriate and adequate care.

I'd like to comment mostly on the first three today. I think that on the subsequent panels on quality and outcomes as well as State activities, we will also be addressing the fourth in more detail, although I think my colleagues will also be addressing the fourth. So, that with some overlap, I am going to limit myself to the first three.

As I said, the last panel indicated very strongly that we need to have for individuals with special needs very good access to specialty care and even subspecialty care, and that that may be counter to the normal model of managed care, where one sees a primary care physician as the access point for all other services. This does not seem like an insurmountable problem. These are individuals who have conditions that are chronic; they are going to be conditions that they have for their full lives. One could imagine that a managed care organization could screen an individual, identify their needs, and assign them to a specialist as their primary care physician.

However, there are a couple of drawbacks to that from the plan's perspective. One is that plans' ability to control cost not only comes from effective utilization review, but it comes from an ability to negotiate with physicians and other providers to get discounts in exchange for providing a significant volume of patients. Also, it involves a much broader array of specialists. Specialists who are going to serve very few patients really takes away a lot of the leverage that plans may have in negotiating with physicians.

The other disadvantage from the perspective of a plan is that having a specialist who is very good at dealing with a particular type of special need can often be a magnet for people with those special needs to be attracted to that plan. That raises the issue of whether the plan is going to be fairly compensated if it actually has a larger population of people with a particular and, furthermore, an expected need.

The issue of rate-setting is the second important issue, and we need to be concerned about it because there is dramatic variation among people who are classified as disabled under the SSI categories. There are some individuals, for example who suffer from blindness, who are generally healthy otherwise and who have very limited expenses. At the other end of the spectrum, is someone who is a quadriplegic, who has quite considerable expenses.

To give you an example of the range of cost differences, in the State of Colorado, the highest cost for the bottom 20 percent of people who are categorized as disabled in the SSI program was $234 a year. That was the top of the bottom 20 percent. The bottom of the top 20 percent, or the 80 percentile, was $10,425 a year. If you were to pay an average rate for all people with disabilities in Colorado to managed care organizations, you would be paying them $3,300 a year, some people costing that plan $400, others costing that plan $10,000.

It is clear we need to vary the rates to pay appropriately for individuals with very different needs as well as to change, or at least mute, the incentives for plans to seek out the individual that is only going to cost $400 and avoid the person who is going to cost $10,000. This is important in protecting both the plans that are unlucky enough to get an adverse selection of people with very high costs as well as to protect beneficiaries by ensuring that plans have adequate resources to serve their needs.

There has been a lot of discussion about varying rates through processes known as risk adjustment where we take into account individual characteristics in setting the rate that we are willing to play a plan, but for the Medicaid program, there has been very little done in terms of actual experience with risk adjustment. At the time of our review, there were only three States that had risk-adjusted rates or were contemplating risk adjustment of their payments for people with disabilities. Most States had the feeling that it was either too costly a process or too administratively difficult a process to undertake. Since that time, there have been other States that are at least considering the adoption of risk-adjusted methods for their payments for people with disabilities in managed care.

The process of risk adjustment involves having to get some information about the individual upon which to base rates. The type of risk adjustment that you may be most familiar with is the Medicare program, which uses largely demographic characteristics, and has been roundly criticized for the inadequacy of that risk adjustment process. In fact, the risk adjusters that Medicare uses account for only about 3 percent of the cost variation among Medicare beneficiaries, and the feeling is that as people join managed care today in the Medicare program, the program rather than saving money, is actually losing money as enrollment grows.

There has been much research and much discussion about moving to a better system, a system based on demographics, on health status or prior utilization, but there are both administrative problems and structural problems with both—administrative problems associated with the problem of trying to gather the information and have it available in a timely fashion so that it can be used. The structural problems relate in part to the incentives that are created. If one uses characteristics of individuals such as diagnosis, there become incentives to upcode the diagnosis, in other words, to overstate the severity of an individual's condition. If one uses prior utilization as a measure of a person's health status, and very frequently, hospitalizations are cited as the service that should be the marker of more expensive individuals, you have created an incentive to hospitalize someone. We don't have the practical experience to know how severe these problems are.

In addition to the rates we pay health plans, besides risk adjustment, there are issues of how we should adjust the structure of rates to try to improve the incentives that exist in our payments to managed care organizations. We would like to try to reduce the potential for profit or loss associated with providing services to any one individual, and this can be done through two different devices. One is reinsurance, which most States have embraced, where plans are protected from having particularly expensive individuals to serve or from having a whole population that is too expensive to serve. As a plan's costs rise, the State or some other reinsurer will share in the excess costs above some level in order to protect the plan.

The other adjustment would be an adjustment known as risk corridors where, in addition to protecting plans against excessive losses, we prohibit plans from having excessive profits. We ask plans whose profits exceed a certain level to share those profits with the Medicaid program in order to discourage the incentive for underservice.

Let me turn now to the final issue that I want to discuss today, which is the issue of establishing the boundaries for service coverage. There are two aspects of that. First, there is the demarcation between the supportive-type services that I mentioned earlier that are needed to compensate for the loss of functioning associated with chronic condition, and second, there are the issues associated with medical and health care.

Long-term care or supportive services distinction and distinction from medical services is important to ensure that there is coverage for all the services that an individual is going to need and that an appropriate payment is made to the managed care plans for the services they are expected to be providing.

Now, having said that, it is not an easy task to divide those two sets of services up, because there is a major gray area in the boundaries that exist between the two types of services.

The second concern about the definition of services or the responsibility for services is something that we uncovered in our review, discussing this with individuals with disabilities, and that is that medical necessity definitions that are often used may not apply well to a population with special needs.

Medical necessity definitions are often focused around rehabilitation, improvement, recovery, whereas individuals with a special need and a chronic condition that is not going to get better may have a very important need for services in order to maintain their existing functioning, to relieve pain that is associated with their condition. Generally, there is not going to be the outcome in terms of recovery or rehabilitation that we often expect from other kinds of conditions.

It is very important as people with chronic conditions move into managed care that these other goals become identified and accepted as legitimate goals and that the plans recognize that services are going to be provided to achieve those kinds of goals. It is a difficult issue in part because we don't have good research to establish the relationship between services and these goals, which are somewhat more subtle than outcomes such as rehabilitation and recovery.

In conclusion let me say that I think the panel 2 weeks ago did an excellent job in terms of expressing the range of needs of persons with special needs as well as expressing some concerns about the capacity and interest of managed care in serving such individuals.

However, management of care is something that such individuals may actually benefit from. We heard very vividly how complex the care is that such individuals require, and having a manager to assist one through the maze of providers seems like an ideal situation. It is a situation that does not always arise in the fee-for-service system, and turning to managed care organizations may provide us an opportunity to increase its prevalence. It seems something that managed care organizations should be capable of undertaking and doing well, but we do need to be very concerned that we pay them appropriately for the tasks and that we hold them accountable for accomplishing the tasks that we have asked them to do.

That is all. Thank you very much. I would be happy to answer any questions that you may have later.

Ms. CHRISTENSEN. Thank you.

Barbara, before you get started, if anybody wants to come up, there are some seats up here.

Barbara.

STATEMENT OF BARBARA MARKHAM SMITH, SENIOR RESEARCH STAFF SCIENTIST, CENTER FOR HEALTH POLICY RESEARCH, THE GEORGE WASHINGTON UNIVERSITY, WASHINGTON, DC

Ms. SMITH. I am Barbara Smith, and it is a pleasure to be here today.

I want to tell you a little bit about the contract study that we did at the Center for Health Policy Research, because in many ways, the study that we did is the empirical confirmation of the guidelines that Bill just set forth.

We took the contracts between the States and the Medicaid managed care companies, and we analyzed the content of those contracts according to specific parameters and guidelines, looking, for example, at what the contracts required in terms of network composition or quality assurance programs or how they handled enrollment.

I want to emphasize that this study looked at the four corners of the contracts only; what was the infrastructure, what was the relationship, what were the requirements and specifications set forth in the contracts. We did not do field visits. We did not do a qualitative studies on which States had better managed care programs than others, and in fact the contract probably could not tell you that because it does not tell you how the States enforce their contracts.

What we found with respect to disabled populations was particularly interesting. Obviously, there is tremendous variation among the States. The States are operating in radically different managed care markets. Some States have had sophisticated managed care markets for years, and the States can easily move into those markets. The plans have been operating in markets that have taken in different types of populations. Other States have just started to develop managed care. Large portions of their populations have never heard of HMOs. So you are talking about dramatically different capability levels within the markets.

Having said that, I think that what we should say in general terms is that the Medicaid managed care contracts tend to parallel the commercial managed care experience, and by that, I mean that it is a managed care system designed to meet the needs of populations that need mainly primary care and that are basically healthy working populations. That is the market that the managed care industry has served over the years.

What is emphasized in these contracts is basically health care systems that are designed to meet the needs of the AFDC population, women and children. When they talk about network specification, to the extent that they mention specialists, and many contracts do not even mention specialists, as part of the network composition, they will mention general pediatricians, they will mention obstetricians. They do not, for example, typically mention pediatric neurologists or geriatric neurologists. They do not talk about multiple specialists being necessary.

Interestingly enough, many of the contracts when they list the services included in the benefit package do not specifically include case management services, which is one of the things that you traditionally associate with managed care. This would indicate that they are not envisioning caring for a population that requires extensive complicated interactive health care services.

There are a few contracts that mention the ability to choose a specialist as a primary care provider in certain circumstances, most typically for prenatal care. Those contracts that do, again, are still, as Bill mentioned, operating on a primary care model as opposed to envisioning a patient care system where somebody may need multiple specialists to be actively engaged on an ongoing basis in caring for the person, and what you are looking for at that point is case management services.

The other thing that the contracts often do not address is the issue of people in ongoing treatment and how you transition them into managed care. If you can, envision somebody coming into this system. The State sets up the Medicaid managed care program, somebody is enrolled in this managed care plan who has had an ongoing relationship with a specialty outpatient clinic at the city's public hospital for years, and they have a detailed plan of treatment and management and a series of prescription drugs as long as your arm. Now they are enrolled in this managed care plan, and all of a sudden, they are no longer dealing with those providers that they have been dealing with. It is not even clear whether they are entitled to renew their prescriptions as they come into this managed care plan, and the contracts have simply not set up the infrastructure, generally, to deal with that.

Now, some contracts have, and when they do, they will, for example, require that the plan pay for the person to continue with their previous provider until such time as the plan can arrange an appointment and evaluation by a plan provider; that they have got to continue with the same prescription drugs until such time as their drug therapy regimen can be reviewed by a plan provider and either changed or reinstigated by a plan provider. But at least there is a hook-up.

Now, that does not guarantee that the person continues to get the same level of care once they get into the plan, that they are going to continue to have access to the same types of specialists, but it at least assures a nexus between the two systems. The issue of continuing the treatment and how you assure continuity of treatment becomes much more complicated, and those few States that have dealt with the issue have basically done so through requiring, again, specifications of certain types of specialists in the system—that they have to have pediatric neurologists, pediatric hematologists, geriatric providers of all different types and subspecialties. Some require that they have, for example—this is not a chronic illness—but specialists with an expertise, for example, in dealing with tuberculosis. Most do not. I would say you almost never see contracts specifying network composition made up of providers who meet condition-specific or disease-specific expertise.

To back track a little bit, the interesting thing is that the disabled population, as Bill mentioned, is really in theory ideally suited for managed care, unlike the AFDC population, which is the population that we are most rapidly bringing into managed care, because the disabled population are “lifers” on the system, and managed care tends to operate best in an environment where they have continued enrollment so that they may have the incentives to provide the preventive care, the maintenance care to maintain function. These people do tend to be very long-term enrollees if you get them in, so that if everything worked according to theory, they would be ideally suited for managed care. But this is an evolutionary process, and what has happened is that the industry in the commercial sector and the private sector has not developed this kind of capability, and therefore, the public sector basically mirrors that.

It is a process that will occur gradually over time, incrementally, but the notion that you can somehow, as if Venus springs from Zeus’ head full-grown, in one fell swoop, transfer large segments of people with complicated health care needs into the managed care system before it is largely ready, I think is going to be a misplaced notion; it is not going to work, and I don’t think the plans are going to be ready to take them, and there is going to be a lot of resistance in the marketplace to integrating them before the capability is there.

In terms of payment issues, we have talked a lot about the need to risk-adjust payment to adequately pay for people who have more complicated health care needs. I think that at this point, it is useful to bring out the fact that we really have not come very far in risk adjustment methodology even for largely healthy populations. So that when we talk about risk-adjusting the payments, we are really—and Bill, you can correct me if I'm wrong—we are really on the frontier. The down side risk of that is that if you do not risk-adjust correctly, obviously, you are either overcompensating or undercompensating the plan. If you are overcompensating the plan, you are going to be basically skimming off other services that need to be provided in other plans to other populations. If you are undercompensating, you run a severe solvency risk. Solvency sounds like a "techie" issue. But everything turns on solvency, because if the plan is running into solvency problems, it means they have cash-flow problems, it means that they are then going to have strong incentives to cut back on services because they can't pay the providers. So that at every step of the way, the solvency of the plan is a critical quality assurance to services being provided.

Now, I just participated in a video conference in Pennsylvania where they are trying to set up their Medicaid managed care program, and they had a lot of questions about how to go about it. One of their questions, interestingly, was should they, could they, set up a separate HMO where they exclusively enrolled all of their AIDS patients and HIV-positive patients. From the clinical perspective that has a certain amount of appeal because it assures that you are going to get a very expert network that knows how to treat these patients, that is going to be basically up-to-speed on all the research, that is going to have a lot of clinical experience—and we found with tuberculosis and with AIDS treatment, like with cardiac bypass surgery, the number of times that a clinician is involved in treatment for a specific condition makes a radical difference in terms of the outcome for a patient.

So the clinical advantages are substantial. The financial problems in terms of how they risk-adjust that payment to that HMO are huge because they are now talking about an HMO comprised exclusively of very high-cost enrollees whose prescription drug expenses alone would be $15,000 a year. What they are also doing, of course, is they are freeing up all the rest of the Medicaid HMOs from any of those responsibilities, so not only are they going to have to pay this HMO a very large capitation, but they are then going to have to ratchet down substantially the other HMOs that are delivering primarily well care, and then their market changes a lot.

So these are the kinds of issues that are coming up on the face of the contract, in the course of the States trying to implement plans. In terms of access to subspecialists, I have to say that there is very little language in the contracts themselves. It does not mean the plans are not providing it, but it means that in terms of getting accountability, measuring it, enforcing that if you have the need to do it, there is just very little there.

In most States, enrollment of disabled people in Medicaid managed care is voluntary; in many States, it is excluded. So again, they are leaving those people in the fee-for-service sector for a reason, and the reason is that the evolution just hasn't gone that far yet.

I want to elaborate a little bit on what the contract showed in terms of medical necessity. I guess I should add a caveat at this point and say that Patsy comes from a State that is the exception to everything that I've just said, and she is going to talk to you about what States that are the exception are doing. Minnesota is the exception in everything, from specifications to market experience to payment level, and I'll let her talk to you about that. So it can be done, and we do have an example of what the future can look like, but for most States, that future is still pretty far away.

In terms of medical necessity, what we find is that the contracts typically do not have a medical necessity definition which mirrors the Medicaid statutory definition of medical necessity. They have what are commercial insurance definitions of medical necessity. A lot of that is tied, again, to treatment for injuries or illnesses, but not conditions, and that does not even get down to the sub-issue that Bill addressed, of whether you are treating a condition or you are providing support services for a condition. That is a level of analysis, which is two or three stages beyond where medical necessity is in these contracts, and frequently, they will include definitions of medical necessity that are not only not coextensive but in fact are inconsistent with the Medicaid definition. For example, the treatment has to be cost-effective. Part of the problem with that is that—I have been in health policy for some period of time, and I do not know how one defines cost-effective medical care. There really is not a consensus on how you evaluate cost-effectiveness.

The other issue, of course, is that under Medicaid, the definition is that the care has got to be reasonably designed to achieve its purpose, and cost-effectiveness is not a consideration. So then, you are left with the States essentially having to pay for care outside the managed care context, so they have paid a capitation, and then they have got to pay for other care that is not covered by the capitation, whether that is intentional or not intentional on the part of the States.

So the medical necessity issue—not only how it is defined, but how it is applied—is a very important issue for the disabled population, and unfortunately, I can say that none of the contracts addresses the issue of evaluating—well, let me back off of "none"—very few—plans are applying medical necessity standards.

I want to talk about some other issues just in terms of accountability that are in pending legislation right now regarding Medicaid and I think Medicare, but certainly Medicaid managed care. In the Senate version of the bill, States must give plans pre-termination hearing rights before a State can terminate a plan for lack of performance. This is unprecedented. We have never in Medicaid or Medicare law given providers pre-termination rights. They are entitled to termination hearing rights, but not pre-termination hearing rights, because of the fact that they may be delivering care in a way that endangers life, and so the need for the State to move—"the State" meaning the sovereign—quickly has always been recognized.

The cases in litigation at the State level indicate that when you give plans pre-termination rights, it is very hard to get them out, to terminate them summarily or to get them out quickly, and in fact it is very hard to get them out before the end of the contract term at all with pre-termination rights.

This has pretty serious implications for the disabled population where, if a plan is not providing services, they are particularly at risk. The State's ability to come in and pull them out of a plan because their enrollment is now the property of the plan becomes very difficult. So these kinds of issues in pending legislation are going to have a significant impact on your ability to move these populations in. If plans have pre-termination rights, you may have to reconsider how quickly and how much and what extent of services you are going to put into managed care plans.

The other issue in terms of what is going on right now that will affect the disabled populations is in the current plans for Medicare and choices of plans. In other words, people now will start getting, as Federal employees get, a packet of materials where they can choose their plan or they can go into the traditional Medicare program. Obviously, the expectation—if you do not choose a plan, you automatically go into the traditionally Medicare program. The default provisions right now, default enrollment into traditional Medicare, are now regarded as somewhat ambiguous. That is, everybody thinks that people who do not enroll are going to go into the main Medicare program, but the language itself is somewhat ambiguous, so that theoretically, it would be possible through regulation or subsequent legislation or whatever to have something else happening with those default enrollees.

I think that if this is an area where everyone has very clear expectations about what they think is going to happen, you need to be sure that the legislative language clearly reflects that expectation. Given the fact that certainly in Medicare managed care, there is also a similar lack of experience with disabled populations, you want to be sure that you are not pushing people into these systems sooner than these systems are ready to take them in.

I think at this point I'll stop.

[The prepared statement of Ms. Smith follows:]

The George Washington University
WASHINGTON DC
MEDICAL CENTER

CENTER FOR HEALTH POLICY RESEARCH

Testimony Before the
United States Senate
Special Committee on Aging

Dirksen Building, Room G-31
Washington, DC 20510-6400

April 29, 1997

Barbara Markham Smith
Senior Research Staff Scientist
The George Washington University Medical Center
Center For Health Policy Research
2021 K Street, N.W., Suite 800
Washington, D.C. 20006

TESTIMONY OF BARBARA MARKHAM SMITH
U.S. SENATE SPECIAL COMMITTEE ON AGING
APRIL 29, 1997

The transformation to managed care may be the most important development since the rise of modern medicine and the use of insurance to pay for health care. This transformation has not only changed the relationship between providers and patients but also has transformed Medicaid from a health care financing program to one of the nation's largest purchasers of private insurance. As a result of the move to Medicaid managed care, the Center for Health Policy Research undertook a nationwide study of the managed care contracts between states and managed care plans.

The study -- which is in its second phase -- has two purposes. The first is to present an overview of the structure and content of the detailed service agreements which describe Medicaid managed care arrangements, including what populations participate and how services are structured. The second purpose is to identify key issues presented by Medicaid's shift from payor to purchaser of managed care.

In a transformation of this magnitude, the states face enormous challenges in their effort to construct integrated delivery systems for poor people and people who have special health care needs, an effort which has no parallel in the private insurance sector. Among the primary challenges is convincing private companies to enter the Medicaid market which offers relatively low capitation rates.

While some states have longstanding experience with managed care and operate in mature markets, many states do not. ~~The~~ transformation to Medicaid managed care is thus in its infancy and is a highly evolutionary process. Accordingly, states generally -- with some notable exceptions -- have largely based their managed care programs on the private employer model that offers primary and acute care to a population composed of relatively healthy young families -- the AFDC population. As with the private sector, states have less experience with managed care for the elderly and disabled.

Theoretically, the dually eligible population is ideally suited to managed care because the complexity of their medical needs lends itself to case management and coordinated care. In addition, dually eligible individuals are enrolled in the Medicare and Medicaid programs on a long-term basis making enrollment more stable and tracking and monitoring of care more feasible to assure clinical coordination and accountability by the plans. The long-term enrollment of dual eligibles also creates more incentives for plans to make investments in care that pay off only in the long term. This stands in stark contrast to the AFDC population which tends to be enrolled in Medicaid only episodically, churning in and out of the program and thereby creating plan disincentives to preventive investments in care.

While managed care should theoretically work well for chronically ill populations, the marketplace to date is only at the beginning stages of development. As seen in the attached table, many states exclude certain disabled populations from mandatory plan enrollment. Whether this exclusion is inititated by the states or by the plans entering the Medicaid market is unclear. Even where disabled populations are included, state efforts to develop the specifications for providing care to chronically ill, disabled people and the frail elderly are in very early stages of evolution.

Because managed care in the private employment sector has been used almost exclusively for healthy, often young, working families, there is simply very limited experience upon which to develop standards for care of the disabled/chronically ill population in a managed care context.

Therefore, states are faced with the challenge of first trying to define what services and structures are needed and then trying to translate these definitions into a contract. The limited experience of plans in caring for these types of populations – in contrast with the traditional medical system who has cared for them almost exclusively – would indicate that these standards should not simply be left to plan discretion.

The early stage of evolution for this process is clearly reflected in the contracts themselves. For example, even where diabled beneficiaries are technically eligible, we can see in the attached table that language on inclusion of specialists in the provider networks is provided in only a minority of state contracts. Indeed, network requirements tend to focus on primary care providers, pediatricians, and maternity care providers -- providers appropriate for the AFDC population. Similarly, provisions dealing with transition arrangements for people in on-going treatment, access to specialists, or special communication services for diabled people are relatively rare. Virtually all contracts specifically exclude long-term nursing home care from plan services.

It is important to note that these problems do not affect only dual eligibles but affect all people with complex health care needs. A disabled child enrolled in a Medicaid managed care plan who is not eligible for Medicare needs the same network sophistication ~~as a~~ dually eligible adult.

Our initial review of 1996 contracts indicates that some states are moving more aggressively to enroll disabled populations. Florida, for example, now specifically incorporates a frail elderly program in its managed care system. Massachusetts and Minnesota are also engaged in a targeted effort to include the chronically ill into their managed care programs. However, these states are the exception, not the rule.

Plans have not shown a willingness to enter this high-risk market for relatively low capitation rates. Setting an appropriate risk-adjusted premium remains a major challenge and it seems unlikely that the integration of the dual eligible population could be accomplished purely on the basis of capitation. Some blending of capitation with stop/ loss provisions and fee-for-service payment would likely have to occur.

Other financing problems are likely to have a chilling effect on the evolution of managed care for this population as well as for the AFDC population. Specifically, the de-linking of welfare and Medicaid will probably cause an actuarial worsening of the Medicaid risk pool. This will occur because instead of relatively healthy families automatically becoming enrolled in Medicaid, people will tend to be enrolled only as they become ill or seek services. As the risk pool worsens while the capitation payment remains stable, the ability to attract plans will decline.

A per capita cap on Medicaid payments would merely intensify this effect. This would occur for two reasons. First, the cap would not reflect the actuarial needs of the worsening risk pool since the cap is based on the existing composition of the risk pool. Secondly, the cap's baseline as proposed is drawn from a period of unusually low Medicaid spending, unlike the welfare cap which is based~~-on~~ a period of high welfare spending, giving states a much more comfortable margin with which to implement new programs during a period of strong economic growth. The combined effect of worsening risk pools and the implementation of a Medicaid per capita cap is the most effective way to bring any further evolution of the Medicaid managed care market to a screeching halt. Efforts to coordinate care for dual eligibles even in the traditional health care sector will become much more difficult under these financial constraints.

The market participation might improve if Medicare funding streams are added to the capitation since Medicare rates are higher than Medicaid rates. This would best be accomplished by having Medicaid and Medicare contribute separately and jointly to the premium rather than trying to merge the funding streams. Separate contributions to the premium would present less risk to the Medicare trust funds. Specifically, Medicare remains liable for Medicare services to the dually eligible population. If beneficiaries fail to get services from plans, Medicare may end up paying twice for the same services – once in the capitation ~~to~~ the plan and again to pay for those services in the fee-for-service sector if the plan fails to perform. This risk is minimized if Medicare is getting direct accountability from the plan and ~~is~~ paying for care only in federally qualified plans. In addition, this payment approach could be used as a mechanism to encourage federally qualified managed care plans to participate in the state Medicaid markets, improving the market for Medicaid-only programs.

In attempting to create better coordination of care and a continuum of care, it is important to recognize that the market may not yet be ready to absorb some of the policy changes considered desirable. Accordingly, substantial acceleration of the enrollment of the dually eligible population into managed care cannot realistically occur until a greater consensus is reached regarding the network and administrative capabilities required to provide and coordinate adequate clinical care. Further work on methodologies for measuring performance and tracking outcomes may also assure that patients benefit from the transition from fee-for -service care from traditional providers to the managed care system. While Medicare funding may be essential to attracting plans to this market, assuring administrative and financial coordination to maintain acccountability to the federal taxpayer remains problemmatical in most states. Given the tenative nature of this market, we believe that slow and careful expansion offers the best option for dually eligible people and for the programs. Because integration into managed care of necessity will occur over an extended period of time, attention should not be diverted from how to improve coordination of care and services within the existing system.

Table 1.a Selected Provisions Related to Disability

Does the contract or RFP address whether: 1) certain categories of recipients are enrolled, 2) specialty providers are available in the network, and 3) special communication services are available for persons with disability?

	AZ	CA	CO	CT	DE	DC	FL FULL	FL MH	GA	HI FULL	HI BH	IL	IA MH	IA SA	KS	KY	ME	MD	MA	MI	MN	MO	MT
Managed Care Enrolled Population (excerpted from Table 1.1 of study)																							
Persons with disability	●	●	●		●		●	●/E	●	E	●		●	●		●			●/E	●/E	E	●/E	●/E
Elderly		●	●/E		●		●/E	E	●	●/E	●		E	E				●		●	●		●/E
Residents of long-term care facilities		E	●/E			E	E	E	E				E	●/E				●/E		●/E	◘/E	E	E
Persons needing long-term home and community care		E	●/E											●				●		●			●/E
Provider Network Standards (excerpted from Table 3.1 of study)																							
Specialty care providers	●	●		●	●		●		●	●	●						●					●	
Translation Services and Cultural Competence (excerpted from Table 3.6 of study)																							
Disability-communication capacity required in network																			●				
Materials in other language or in form useful to people with disabilities	●	●					●	●	●			●			●	●			●		●	●	
Services for persons with speech, language, hearing, or vision related disabilities														●					●		●	●	●

● means that an issue was addressed in the contract or RFP.
E means that the enrollment category has been explicitly excluded from the contract or RFP.
●/E means that certain groups within an enrollment category have been explicitly excluded from the contract or RFP.
◘ reflects state revisions of contracts or RFP subsequent to study period and incorporated at state request.

Table 1.b Selected Provisions Related to Disability

Does the contract or RFP address whether: certain categories of recipients enrolled, 2) specialty providers available n the network, an 3) speial communication ervics are available for persons with isability?

NE		NH	NJ	NY		NC	OH	OR		PA	RI	TN	TX	UT		VT	VA	WA		WV	WI	
FULL	MH			FULL	MH			FULL	MH					FULL	MH			FULL	MH			
																						Managed Care Enrolled Popoulation (from Table 1.1 of study)
●	●		●	●	●	●			●	●		●		●	●	●	●		●	●	◘	**Persons with disability**
●	●				●				●	●		●		●	●	●	●		●		◘	**Elderly**
E	●		E	●/E					●			●					●		●	E		**Residents of long-term care facilities**
●/E	●			●					●			●					●		●		◘	**Persons needing long-term home and community care**
																						Provider Network Standards (from Table 3.1 of study)
●			●	●		●	●			●	●	●				●	●			●	◘	**Specialty care providers**
																						Translation Services and Cultural Competence (excerpted from Table 3.6 of study)
			●																			**Disability-communication capacity required in network**
●	●		●	●		●	●		●		●					●				●	●	**Materials in other language or in form useful to people with disabilities**
●	●	●	●	●						●			●		●	●		●		●		**Services for persons with speech, language, hearing, or vision related disabilities**

● means that an issue was addressed in the contract or RFP.

E means that the enrollment category has been explicitly excluded from the contract or RFP.

●/E means that certain groups within an enrollment category have been explicitly excluded from the contract or RFP.

◘ reflects state revisions of contracts or RFP subsequent to study period and incorporated at state request.

[Smith]

Variations in contract language: Medical necessity definitions

Federal law requirement for **Medical Necessity**:

"(b) Each service shall be sufficient in amount duration and scope to reasonably achieve its purpose.

(c) The ...agency may not arbitrarily deny or reduce the amount duration or scope of a required service...to [a] recipient solely because of the diagnosis, type of illness or condition

(d) The agency may place appropriate limits on a service based on such criteria as medical necessity or on utilization control procedures."

42 CFR 440.230

Variations in contract language: Medical necessity definitions

"The health care services listed below shall be provided by the contractor to enrollees as covered benefits rendered under the terms of this contract. Provision of these services shall be equal in amount, duration and scope as established by the Medicaid program, in accordance with medical necessity without any predetermined limits unless specifically stated, and set forth in the Medicaid Provider Manuals..."

New Jersey Contract

Variations in contract language: Medical necessity definitions

"The term 'medical necessity' and 'Medically Necessary' with reference to a covered service means health care services and supplies which are medically appropriate and 1. necessary to meet the basic health needs of the Client; 2. rendered in the most cost effective manner and type of setting appropriate for the delivery of the Covered Services; 3. consistent in type, frequency and duration of treatment with scientifically based guidelines of national medical research or health care organizations or government agencies; 4. consistent with the diagnosis of the condition; 5. required for reasons other than the convenience of the Client or his or her physician; 6. no more intrusive or restrictive than necessary to provide a proper balance of safety, effectiveness, and efficiency; 7. of demonstrated value; and 8. a no more intensive level of service than can safely be provided. The fact that the Physician has performed or prescribed a procedure or treatment or the fact that it may be the only treatment for a particular injury, sickness or mental illness does not mean that it is Medically Necessary. Services and supplies which do not meet the definition of medical necessity set out above are not covered." *Nebraska Contract*

Variations in contract language: Relationship between managed care plans and other parts of the health system

"This section implements sections 1902(a)(11)(C) and 1902(a)(53) of the Act, which provide for coordination of Medicaid with the Special Supplemental Food Program for Women, Infants, and Children (WIC) under section 17 of the Child Nutrition Act of 1966...

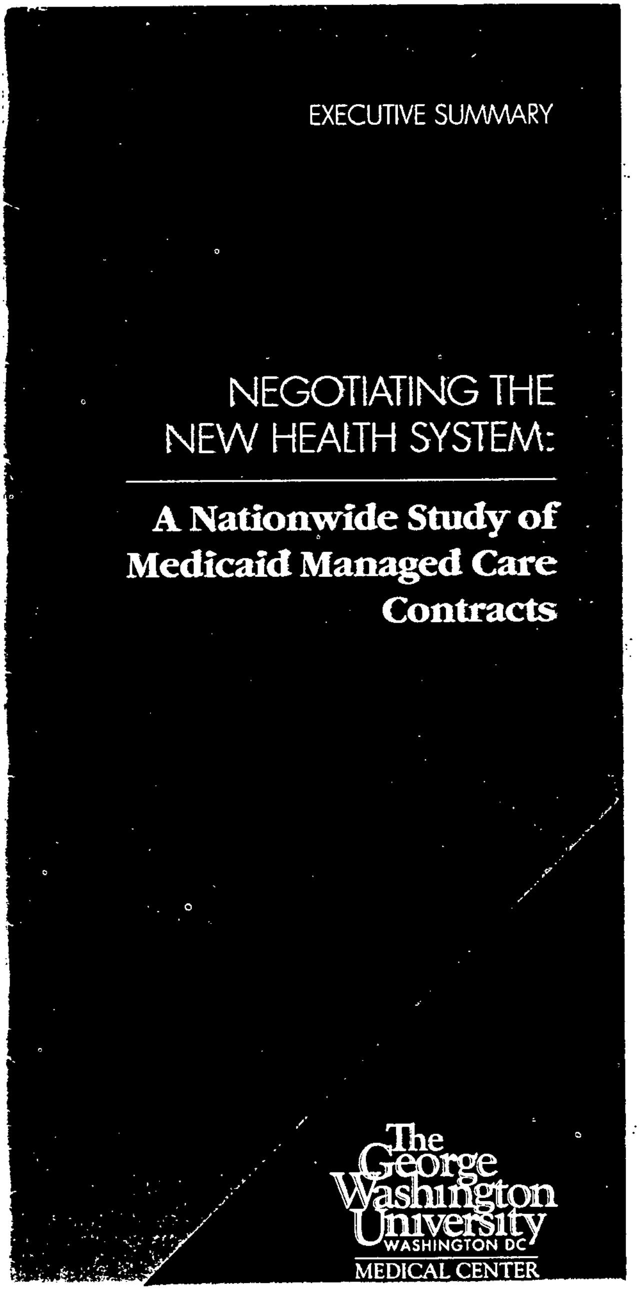
A State Plan must provide for-
(1) Coordinating operation of the Medicaid program with the State's operation of the Special Supplemental Food Program for Women, Infants, and Children...

(3) Referring individuals described under paragraphs (c)(2)(i) through (iv) of this section to the local agency responsible for administering the WIC program." *42 CFR 431.635(c)*

"This section implements sections 1902(a)(11)(C) and 1902(a)(53) of the Act, which provide for coordination of Medicaid with the Special Supplemental Food Program for Women, Infants, and Children (WIC) under section 17 of the Child Nutrition Act of 1966...

A State Plan must provide for-
(1) Coordinating operation of the Medicaid program with the State's operation of the Special Supplemental Food Program for Women, Infants, and Children...

(3) Referring individuals described under paragraphs (c)(2)(i) through (iv) of this section to the local agency responsible for administering the WIC program." *42 CFR 431.635(c)*



EXECUTIVE SUMMARY

NEGOTIATING THE NEW HEALTH SYSTEM:

A Nationwide Study of Medicaid Managed Care Contracts

The George Washington University
WASHINGTON DC
MEDICAL CENTER

Executive Summary

I. Setting the Context

1. The Transformation to Managed Care

The transformation to managed care may be the most important development since the rise of modern medicine and the advent of insurance as the central means of paying for health care. A relative rarity only twenty years ago, managed care insurance now claims enrollment of over 150 million Americans. This transformation not only changed the relationships between patients and providers but also transformed Medicaid from fee-for-service government health insurer into a large-scale purchaser of private insurance.

This study has two purposes. The first is to present an overview of the structure and content of the detailed service agreements which describe Medicaid managed care arrangements. The second is to identify key issues presented by Medicaid's shift from a government insurer to one of the nation's largest purchasers of managed care. This study should not be read as an analysis of the quality of Medicaid managed care systems generally, nor should it be read as an analysis of the entire legal framework in which Medicaid managed care operates.

This analysis of 37 states' Medicaid managed care contracts should be viewed as a baseline. Medicaid agencies face a major challenge in their efforts to buy managed care for many reasons, not the least of which is the need to convince managed care companies with limited experience with Medicaid populations to become active participants in their states' programs. Significant changes can be expected over time as Medicaid agencies gain greater purchasing experience and as the Medicaid program itself is recast to reflect this basic shift from government insurer to insurance purchaser. Indeed, the annotated tables which accompany this report contain examples of states' reported modifications and improvements made between 1995 and 1996 alone.

2. The Transformation of Medicaid from Government Insurer to Managed Care Purchaser

The evolution of Medicaid from government insurer to managed care purchaser began slowly and then accelerated rapidly. Over the past decade both Congress and the Clinton Administration have steadily expanded the tools available to state Medicaid agencies to mandate managed care enrollment and purchase fully integrated service delivery systems. These legal tools include Section 1915(b) and Section 1115 of the Social Security Act. Section 1915 permits waivers of the Medicaid freedom-of-choice law provisions in order to permit states to mandate enrollment in managed care. Section 1115 goes much further, permitting states to obtain waivers of numerous aspects of federal Medicaid law, including rules on eligibility, benefits, provider qualification and payment rules, and administrative requirements. Since 1993, the Clinton Administration has used this authority to permit states to institute large-scale mandatory managed care demonstration projects.

As a result, managed care enrollment among Medicaid beneficiaries has grown dramatically in recent years. In 1983, 800,000 Medicaid beneficiaries were members of managed care plans; by 1996, the number had surpassed 12 million and is expected to grow steadily over the next several years. Nearly all states mandate managed care enrollment for at least some portion of their populations, but not all states contract with full-risk managed care organizations (i.e., those at risk for both ambulatory and inpatient care costs).

Two key factors distinguish managed care arrangements from other forms of insurance: 1) the nature of the contractual promise between managed care companies and group purchasers, and 2) the relationship between companies and their providers. Managed care contracts involve both insurance coverage and a promise of health care. Managed care companies contract to furnish or arrange for insured services through a specified network of health professionals, institutions, and other providers. Under managed care, a company's contractual promise to provide care devolves to its providers; as a condition of participation, providers generally must agree to accept patients who are referred to them by the company at rates which the company pays for care.

Depending on the size of the premiums paid, managed care plans can be either tightly or loosely structured health care arrangements. Loosely-structured or "high option" plans (typically point-of-service HMOs and preferred provider organizations) permit members to seek some or most covered services from non-network providers for a somewhat higher fee. However, because high-option products are more expensive to purchase and are designed for persons with discretionary income to pay higher copayments, they are not used by Medicaid agencies. Thus, the Medicaid managed care system provided under a contract is effectively the only source of covered services for enrollees, with the exception of emergency care. No other purchaser faces quite the same challenge of building a comprehensive, fully-integrated network of services for its enrolled population.

Several aspects of Medicaid make purchasing managed care especially complex: a) Medicaid enrollment is very short, lasting less than one year on average; b) beneficiaries are in poorer health than their non-low income counterparts and may represent a greater cost to managed care organizations; c) Medicaid beneficiaries tend to live in communities with a limited number of health providers, making it difficult to build networks in these communities; d) Medicaid enrollees are more likely to be poor, less well educated, very young or very old, and physically or mentally disabled; e) Medicaid beneficiaries who have complex needs may receive care from several distinct components of the health care system such as: child welfare agencies, alcoholism and addiction treatment and prevention programs, local public health agencies, school health systems, or chronic disease specialty clinics; and f) because they tend to lose their Medicaid coverage frequently, Medicaid beneficiaries need coordination between managed care organizations and sources of care when they are uninsured.

3. The Legal Framework for Medicaid Managed Care

The organizational and legal framework in which Medicaid managed care arrangements operate is complex. The framework can be thought of as a pyramid with multiple layers, each of which is essential to the proper functioning of the managed care system.

- **Self-regulation**
  At the base of the pyramid are self-regulating activities such as industry accreditation and codes of conduct, professional training and education, collection and analysis of performance data, and other efforts to control and promote quality. Many of these efforts tend to be adopted by the industry in response to consumer concerns.

- **Contracts**
  At the next organizational layer are the agreements which establish the operational structure of the managed care arrangements purchased by the state. It is the contract that brings to life the transformation of Medicaid from a reimbursement program to a managed care purchaser. Under principles of contract law and interpretation, clarity and precision are crucial. This is particularly true for the drafter of the agreement, since courts will interpret ambiguities against the party who drafted the document. For public agencies, this rule represents a marked departure from the rules governing judicial review of agency regulations, which call for broad discretion to be given to regulatory agency interpretations of law.

- **State and Federal statutory and regulatory law**
  At the top levels of the pyramid are the many federal and state laws that govern the provision of managed care services to Medicaid beneficiaries. Beyond Medicaid laws, state insurance, business licensure, and public health laws may contain numerous requirements which apply to both managed care companies and Medicaid agencies.

II. The Four Major Elements of Medicaid Managed Care Contracts and Key Findings

1. Defining the Managed Care Service System

Contracts between states and managed care plans identify: a) the attributes and structure of the purchased health care system states expect plans to make available to their clients; b) the methods that plans will employ in delivering services; and c) the process for verifying the attributes of plan service systems and measuring plans' performance. There is no real precedent for this large-scale and detailed effort to articulate in writing agencies' expectations of how the entire health care system will operate for beneficiaries. In this regard, state Medicaid agencies are charting an innovative and unequaled course in attempting to address how health care arrangements for poor people (many of whom have special health care needs) should function.

- **Findings on Contract Provisions Related to Medicaid Managed Care Service Systems**
  This study found that:
  - States are not buying "off-the-shelf" products. Instead they are either designing or requiring plans to design custom delivery systems for Medicaid enrollees.
  - Contract delivery specifications tend to deal with the overwhelmingly primary health care needs of a relatively healthy, young family population. They are only beginning to address in depth the specific capabilities plans will need in order to serve high need sub-populations (e.g. disabled children or adults, persons with HIV/AIDS, or the elderly).
  - States vary substantially in the amount of discretion they accord to plans in structuring service delivery systems. Some states provide detailed specifications on network composition, access, and other measure, while others provide more discretion to plans.

2. Translating Medicaid Benefit and Administrative Requirements into Contract Language

Medicaid managed care contracts identify which federal and state benefit and administrative duties state agencies desire to have contractors to carry out on their behalf. Contracts between state agencies and managed care plans generally do not cover all of the services and benefits included in a state's Medicaid plan. This means that Medicaid managed care enrollees have two sources of coverage: 1) their managed care membership, which covers the classes and levels of services included in the agency's service agreement with the contractor; and 2) their basic Medicaid coverage, which pays for those Medicaid-covered items and services that are not included in the plan's contract and instead are paid for directly by the Medicaid agency.

In developing a contract with managed care plans, states must first identify *which* services and duties are to go into their contracts. Agencies then must *draft* the actual terms and conditions with sufficient precision and clarity to ensure that the description of the plans' coverage duties is correct and that contracts do not leave a state either administratively or financially liable for care and services that it believes are covered under the contract. While state agencies always remain liable for the proper performance of their contractors, ambiguous contract terms can render agencies obligated for the direct provision of care and services in ways which they did not contemplate.

- **Findings on Translating of Medicaid Benefit and Administrative Requirements Into Contract Language**
  States vary in:
  - The classes of services and benefits they include in their contracts, although certain services commonly associated with very sick and disabled beneficiaries (e.g., extended nursing home care, home and community based care) typically are excluded from the scope of the service agreements.
  - The extent to which certain classes of services are included in their contracts (i.e., coverage of all medically necessary physical therapy services versus coverage of only a certain number of visits annually).
  - The degree of guidance they give plans regarding the medical necessity criteria plans are required to use in making coverage determinations or the procedures that plans should follow in making coverage determinations.
  - The extent to which they permit contractors to apply standard insurance coverage exclusions principles and exclude coverage for certain services that are otherwise included in the contract.
  - The extent to which they explicitly identify for their contractors services that the state agency will continue to cover directly under their residual Medicaid plans, as well as those that are not covered services.
  - The conformity of state contracts to the wording of the federal statute and regulations to describe the covered services for which they are contracting.

This disjunction between federal legal definitions and states' contractual definitions has several potential consequences. First, it may dilute the level of coverage for enrollees who may not understand that certain services (or aspects of services) remain available directly through the state Medicaid agency and are simply not included in the managed care benefit package. Second, the disjunction may create contractual "gaps" that leave a state financially obligated to pay directly for certain items and services that it intended to include in the contract. Third, it may cause confusion for plans and participating providers regarding what is and is not covered. Fourth, wide variation in service terminology means that there may be substantial state-to-state differences in the types of care within classes of benefits that, in fact, may be covered under state contracts.

3. Defining Medicaid Managed Care Relationship with the Larger Health System

While Medicaid managed care represents an unprecedented effort to purchase complete and integrated health service delivery arrangements, these systems nonetheless are only a component of the larger health care system in which they operate. Medicaid beneficiaries may be served by more than one part of the health care system because they may have needs that go beyond the benefit package bought from managed care companies. Moreover, short Medicaid enrollment periods mean that patients (not at their own choice) will have to move between health care systems.

DETACH HERE

ORDER FORM

Please send me:

	Quantity	Cost
Negotiating the New Health System: A Nationwide Study of Medicaid Managed Care Contracts. Volume I. 100 pages.	______	$25.00
Negotiating the New Health System: A Nationwide Study of Medicaid Managed Care Contracts. Volume II (Part I and II). 2000 pages.	______	$100.00
TOTAL	______	______

Pre-payment required.

Please make check payable to:
Center for Health Policy Research/GWU
2021 K St., NW Suite 800
Washington, DC 20006
Phone: 202-296-6922
Fax: 202-296-0025
ATTN: CONTRACT STUDY

Finally, relationships with public health agencies, in particular, are needed to ensure that key public health functions can be properly carried out.

- **Findings on the Relationship Between Managed Care Plans and the Large Health Care System**
  Our study indicates that:
  - States are just beginning to grapple with an exceedingly complex issue which was never satisfactorily addressed in the fee-for-service system: the coordination of care between different entities and different type of providers.
  - States are not currently in a position to purchase continuous enrollment in managed care for Medicaid beneficiaries, creating gaps in coverage.
  - Few contracts contain specifications for referrals to non-network agencies or providers or for coordination of treatment plans ordered by courts, school systems, and other parts of the social service or justice system.
  - States generally focus on encounter, grievance, and financial data to measure plan performance, and only a few focus on issues related to plan integration with larger system, the process of care, and population health outcomes.
  - Coordination between managed care and public health agencies is largely unspecified, and contracts do not cover traditional public health functions.

Send to:

Name: ____________________

Title: ____________________

Organization: ____________________

Address: ____________________

____

Phone: ____________________

4. Constructing Business Terms and Relationships

Finally, Medicaid managed care contracts define the nature of the business relationship between the buyers (the state Medicaid agencies), the sellers (the managed care organizations), the providers, and the enrollees. The terms of the contract can reflect both the practical and financial aspects of the business arrangement that guarantee the stability of performance, as well as the purchaser's judgment about how the contract duties should be performed.

Because the purchase of an integrated health delivery system is a business transaction, the state has a strong interest in assuring that its contractors remain a financially viable businesses capable of delivering the contracted services. Perhaps of greatest importance, states must be able to address effectively contractor non-compliance with its contracted duties.

- **Findings on Constructing Business Relationships**
  This study shows that:
  - Reflecting the recognition that purchase of a health care system for the poor is a business transaction, all states have included some provisions defining the terms and relationships necessary to establish the business framework for Medicaid managed care contracts.
  - States vary in the degree to which they rely on state insurance regulation rather than the contracts to regulate the financial stability of plans.
  - States differ in the degree to which they give plans the discretion to design enrollee and provider grievance procedures and in the degree of specificity they use in defining minimum procedures.
  - While all states establish sanctions for non-performance, states vary in the range of sanctions applied and in the degree to which specific sanctions are tied to specific performance measures.
  - Even in states with detailed purchasing and performance specifications, there may be no clear link between particular specifications and particular sanctions.

III. Summary of Recommendations

1. Defining the Medicaid Managed Care Delivery System

We recommend that a joint, multi-disciplinary Medicaid managed care purchaser's initiative be undertaken to develop a consensus on model practice-style specifications in contractors' service delivery systems.

This consensus building exercise is similar to the one used to develop the quality performance measures under the HEDIS system but would instead focus on what should go into contracts with plans. Because contracts are legally enforceable promises, the great challenge is to identify those aspects of service delivery which are so crucial that their legal enforcement should be possible. Medicaid purchasers should join with consumers, public agencies, health plans, providers, and experts to develop a useful and practical body of information on key service design elements for different Medicaid populations. These elements should then be translated into contract language to be of maximum use to states.

2. Translating Medicaid Benefit and Administrative Requirements into Contract Language

We recommend that HCFA work jointly with the states to develop detailed purchasing specifications and model contract language related to states' statutory and regulatory benefit and administrative duties.

Translating public duties into private contract language is exceedingly difficult. Our recommendation then is to give states model language that could help avoid inadvertent discrepancies in contract language that dilute the value of covered benefits and leave states with unintended financial liability for benefits that inadvertently were omitted from contracts.

3. Defining the Relationship of Medicaid Managed Care to the Larger Health System

Stabilizing Medicaid managed care enrollment: **To maximize continuity of care and encourage the development of a more stable patient base for managed care plans, we recommend that Medicaid be modified to guarantee annual periods of eligibility for enrollees in order to extend year-long coverage status to individuals enrolled in managed care plans.**

Maintaining the public health infrastructure: **We recommend that the same purchasers group which is organized to address service delivery matters also address the question of how to integrate managed care plan activities into the broader population based health care activities undertaken by public health agencies. We also recommend that Congress give express consideration to how these population-based activities will be financed in a post-managed care world, where revenues from personal health services previously furnished by such health agencies may decline, thereby creating a need for supplemental sources of funding.**

Coordinating the services of managed care plans with health providers for the uninsured and the need to finance care: **To avoid the loss of uncompensated care capacity at a time when the number of low income beneficiaries without Medicaid may rise substantially, we recommend that policy makers develop alternative means of financing uncompensated care, as well as coverage for the uninsured. Such a financing subsidy should be tied directly to the proportion of uninsured patients who are served by individual providers, in order to encourage the best targeting of available funds.**

Inter- agency coordination: **Medicaid managed care purchasing probably is most effective when it is done as a joint enterprise among state agencies; for this reason we recommend that any effort to begin to address the issues raised by this study involve the range of agencies and interests affected by the outcome of managed care.**

There is a need to systematically identify and develop a spectrum of possible approaches to the issue of managed care plans' relationship to other parts of the health care system so that contractual performance expectations can be fashioned and properly measured.

The most important integration areas that should be explored are those involving public health agencies, special education and early intervention programs, mental health and substance abuse treatment and prevention agencies, child welfare and juvenile justice systems, and state welfare-to-work initiatives.

We recommend that the purchasers' initiative on service delivery specifically develop standards related to referral arrangements among public agencies and other entities that traditionally deliver services to the Medicaid population.

4. Constructing Business Terms and Relationships for Managed Care Plans

We recommend the development of model grievance procedures for use in Medicaid managed care disputes.

The variation in the degree to which states tie specific sanctions to specific failures of performance indicates an absence of consensus on what performance indicators may be the most useful and how to create incentives for performance in key areas. This makes individual grievances all the more important. We recommend the development of model grievance procedures that are consistent with states' fair hearing obligations under Medicaid. The procedures should address both process and time frames and should include expedited procedures for reviewing prospective service denial.

With respect to grievance procedures, a consensus should be developed regarding the identification of procedural requirements that are most likely to assure that specific problems are addressed within defined time frames and that problems which reflect more systematic performance failures are identified and corrected. In Medicaid this is especially crucial given states' continuing obligations under federal law to ensure fair hearings for beneficiaries before aid is denied or reduced.

We recommend the establishment of a multi-disciplinary task force to develop uniform contract-based performance indicators as well as sanctions and incentives that are tailored to correct an identified performance deficiency.

Both standardized grievance procedures and targeted sanctions are essential elements in assuring internal and external accountability by the plans and provide essential tools in strengthening the purchaser's ability to achieve its health delivery and fiscal goals in transforming Medicaid.

Ms. CHRISTENSEN. I'm going to interrupt again. Hope Hegstrom of our staff is here, and she is going to pass around some question forms, and at the end we will gather them up and read questions for our panelists today. Barbara, I think we did get some of your materials here and copied on the table. We have been bringing in materials, so check the table before you leave today and see if there is anything that you have not picked up yet.

Patsy.

STATEMENT OF PATRICIA A. RILEY, VICE PRESIDENT OF GOVERNMENT PROGRAMS, POLICY AND PLANNING, ALLINA HEALTH SYSTEM, MEDICA HEALTH PLANS, MINNEAPOLIS, MN

Ms. RILEY. My name is Patsy Riley, and I am Vice President of Government Programs for Medica Health Plans, which is part of Allina Health System. Allina Health System is a not-for-profit, integrated health delivery organization comprised of 17 hospitals, 600 employed physicians and a one million-member health plan called Medica—every time I hear that "one million," it astounds me, because there are only 4 million people in Minnesota, so when you think about that—we contract with over 7,000 physicians and hundreds of hospitals, nursing homes and other allied providers throughout Minnesota.

Medica has over 160,000 Government enrollees, 80,000 of which are enrolled in the Prepaid Medical Assistance Program, or PMAP, which Susan mentioned earlier. I was one of the architects of that program, and just a little bit of career advice: Be careful what you design as a State employee, because if you have to run it as a private sector individual, there are days when I wake up and ask, "Who the hell designed this?" when I was one of the people who did—so keep that in mind.

Our PMAP membership includes AFDC and the elderly, and currently, Minnesota does not mandate the disabled population to enroll in a managed care organization. However, as Susan mentioned before, we did try that as a part of the PMAP demonstration project 10 years ago, and it was not successful; and a lot of what I am going to talk about today in terms of my comments will focus on the lessons that I think we learned from that and some recommendations for where I think we go from here.

Medica has participated in the Prepaid Medical Assistance Program since its inception in 1985. I have made available to the Committee a copy of an article which describes our Medicaid program and focuses on several of our accomplishments to date, and some of the highlights in that article talk about a transportation called Provide-a-Ride. We are basically in the cab business, and Provide-a-Ride provides 90,000 cab rides every year to doctor appointments, dentist appointments, hospital visits and so on, for our Medicaid members.

We also do welcome calls to explain the health plan and determine need for services. We do a mini health assessment to find out if they are pregnant, if they smoke, if they have HIV or whatever, and then try to direct them to the necessary services.

We have hired multilingual staff who are fluent in Spanish, Russian, Chinese, Hmong, and Vietnamese, representative of all the populations we serve in our Medicaid program. We also create multilingual materials; all of our enrollment and communication materials are in the above-mentioned languages. We hire social workers who are basically problem-solvers. Their role is to figure out, based on the mini health assessments that we do, where services are needed, and they go out and connect this population with nonmedical services.

These are just a few of the programs that we have added since beginning to work with low-income and elderly populations 10 years ago. These innovations are illustrative of the important value-added features that managed care organizations must be willing to develop and invest in in order to adequately meet the needs of nontraditional managed care populations.

Each of the above programs was designed based on barriers to getting needed services that have been identified by either members or our providers. We quickly learned that coverage does not equal access, and that by merely enrolling the AFDC and the elderly populations into a managed care plan and expecting them to then look and act like a commercial population is a big mistake indeed.

Our experience with the AFDC population and the elderly have taught us several lessons. No. 1 is humility. We did not have all the answers, and we do not have all the answers now. We are continuing to learn how to better service low-income individuals on a daily basis.

No. 2, one size does not fit all. Small programs targeted to unique member needs like high-risk pregnant mothers or children with asthma or dual-eligibles are much more effective than a population or blanket approach.

No. 3, listening to the members. Our Medicaid members have taught us how to design services for them. We are not the experts.

No. 4, you cannot separate health and social needs. A member who is given a prescription which must be refrigerated and who has no refrigerator will not and cannot be compliant. Knowing the individual's social supports or lack thereof, their housing situation, and so on, is critical to maximizing the effectiveness of health care services received.

As we now begin to explore again enrolling the disabled population, we are trying to learn from these lessons of the past. The rest of my testimony will provide insight and recommendations for how managed care organizations can effectively develop programs to meet the needs of this unique population.

I believe the disabled population—and I have been in this business for 10 years—represents the great challenge of all for managed care organizations, and I have been cheered by some of the comments about how this population should be able to naturally fit into this, because I perceive that there still may be some barriers or reticence on behalf of managed care in regard to this population, and it is for the challenges that I am going to cite below.

We have talked briefly about this, but the disabled individuals who are covered by Government programs are on these programs not necessarily because they are low-income but because they are medically needy. Unlike any other population that we enroll, where you will have some healthy and some who need services, the disabled population will all need services—some a little, some a lot, but they will all need some kind of medical services. So I would agree with some of the comments here earlier about the viability of a primary care model and so on.

Second, their health status can be much less predictable and more volatile than any other Medicaid or commercial population that we enroll.

Third, managed care organizations—and we heard about this earlier—often do not have contractual relationships with the types of care settings and care providers who provide services to this population.

Fourth, rate-setting is particularly challenging for the disabled population because of the volatility of health status and the unique special needs that are often present.

Fifth, managed care organizations, because of liability and risk management issues, may feel that they need to credential and certify providers, thereby potentially over-medicalizing services that are provided by friends and families of the disabled.

Sixth—Barbara mentioned this—disabled individuals often have longstanding relationships with certain providers, many of whom have been providing services to those populations often for years. If the disabled individual is required to change providers, the impact could be disruptive to the care plan and demoralizing for the member.

Having listed those challenges, I also think there are positive opportunities for managed care and the disabled population. No. 1, if the disabled population represents the last basion of fee-for-service medicine, and reimbursement continues to decline, this population runs the risk of decreased access to health care services and programs and the possibility of the creation of a two-tiered system, one for the disabled and one for the rest of us.

No. 2, managed care through its purchasing power can reduce the cost of certain services and drugs needed by the disabled person.

No. 3, managed care can act as an advocate for the disabled member—and we have certainly seen that in my health plan with the AFDC and elderly populations—ensuring access to quality services.

No. 4, managed care, through its credentialed network, can measure quality outcomes on behalf of the members.

I have tried to list both the opportunities and challenges of enrolling the disabled population into managed care. In numerous conversations I have had with disabled individuals and advocates in preparation for this testimony as well as the work we have done over the last 12 years, I have put together a list of recommendations for next steps.

No. 1, move slowly, deliberately, and with caution. We are not ready to go statewide in Minnesota, much less nationwide, with moving the disabled into managed care. We should look at developing pilots and demonstrations and then evaluate the outcomes of those pilots.

No. 2, we must include the disabled in the design, implementation and evaluation process. My experience with many disabled individuals underscores the need to first look at what services are being delivered now, where can improvements be made, and how do we ensure that we measure the outcomes. Disabled people will tell you they know where dollars can be saved, but managed care must include them in this discussion.

No. 3, we must develop a credible risk adjustment payment methodology for this population. There is a lot of talk about this going on with Medicare and Medicaid, but we need to also be addressing it with the disabled population.

No. 4, managed care will have to address some of its utilization controls and benefit limits. They may not be appropriate for a disabled population.

No. 5, managed care will also need to be aware of the concern by many in the disabled community about the over-medicalizing of the personal care attendant model as an example. Managed care will need to balance its risk management and quality assurance needs with the appropriate independence agenda of the disabled population.

No. 6, managed care organizations must build trust with disabled members. If a disabled member is mandated into joining an HMO, and they are unhappy or mistrustful, they run the risk of noncompliance or open defiance of care regimens.

No. 7, managed care must learn to contract with a new set of players who interact and provide care for disabled people. Community-based agencies, long-term care facilities, personal care attendants, special home care and transportation agencies are just a few examples.

No. 8, the service coordination role for this population will need to be discussed. Where does it reside—at the county level, the State, a private agency, or the HMO? There are pros and cons to each approach, and perhaps we should test each model and decide which is best.

Finally, No. 9, the term managed care itself may be a problem. Many disabled individuals feel that they have “managed their care” quite well, thank you, and they are unclear as to what value the managed care organization brings to the table. Managed care organizations will have to continue to educate people about the value they bring around network management, claims processing, credentialing of providers, measuring quality, aggregating insurance risk, profiling physicians, and service and product discounts, to name a few.

On behalf of my peers and colleagues here, I thank you for the opportunity to present this information, and I will stop here and take any questions that you may have.

[The prepared statement of Ms. Riley follows:]

5601 Smetana Drive
P.O. Box 9310
Minneapolis, MN 55440-9310
612-992-2900

MEDICA.
HEALTH PLANS
ALLINA HEALTH SYSTEM

Presentation to Senate Special Committee on Aging

Tuesday, July 8, 1997

By
Patricia A. Riley
Vice President, Government Programs
Allina Health System

Members of the Committee, my name is Patricia Riley and I am Vice President of Government Programs for Medica Health Plans which is part of Allina Health Systems. Allina Health System is comprised of 17 hospitals, 600 employed physicians and a 1 million member health plan called Medica, which contracts with over 7000 physicians and hundreds of hospitals, nursing homes and other allied providers throughout Minnesota.

Medica has over 160,000 government enrollees, 80,000 of which are enrolled in the Prepaid Medical Assistance (PMAP). Our PMAP membership includes AFDC and the elderly. Currently, Minnesota does not mandate the disabled population to enroll in a managed care organization (MCO) however, this is being developed as we speak.

Medica has participated in the Prepaid Medical Assistance program since its inception in 1985. I have made available to the committee a copy of an article which describes our Medicaid program and focuses on several of our accomplishments to date. Program highlights include:

- A transportation program called Provide-A-Ride, which provides 90,000 cab or bus rides to doctors appointments each year.
- Welcome calls -- to explain health plan and determine need for services.
- Multi-lingual staff -- staff are fluent in Spanish, Russian, Chinese, Hmong, and Vietnamese.
- Multi-lingual materials -- enrollment and communication materials are printed in multiple languages.
- Social Service Coordinators -- problem solvers who connect members to non-medical services.

These are just a few of the programs we have added since beginning to work with low income and elderly populations ten years ago. These innovations are illustrative of the important value added features managed care organizations must be willing to develop and invest in, in order to adequately meet the needs of non-traditional managed care members. Each of the above programs was designed to address barriers identified by our members and our providers, to getting needed services. We quickly learned that coverage does not equal access, and by merely enrolling the AFDC and elderly populations into a managed care plan and expecting them to look and behave like a commercial population is a big mistake indeed.

Our experience with the AFDC populations and the elderly have taught us several lessons:

1. *Humility* --
   We did not have all the answers and we are continuing to learn how to better serve low income individuals.

2. *One Size Does Not Fit All* --
   Small programs targeted to unique members needs (i.e. high risk pregnant mothers or children with asthma) are more effective than a population or blanket approach.

3. *Listening to the Member* --
   Our Medicaid members have taught us how to design services for them. We are not the experts.

4. *Cannot Separate Health and Social Needs* --
   A member who is given a prescription which must be refrigerated, but has no refrigerator, will not be compliant. Knowing the individuals social supports, housing situation, etc. is critical to maximizing the effectiveness of health care services received.

As we now begin to explore enrolling the disabled population, we are trying to learn from these lessons of the past. The rest of my testimony will provide insight and recommendations for how managed care organizations can effectively develop programs to meet the needs of this unique population.

The disabled population truly represents, I believe, the greatest challenge of all for managed care organizations. This is true for a number of challenges sited below:

1. The disabled individual covered by government programs are on these programs not because they are low income, but because they are medically needy. Many require extensive medical care to address chronic conditions as well as acute episodes of care.

2. Their health status can be much less predictable and more volatile than other Medicaid or commercial populations.

3. Managed care organizations often do not have contractual relationships with the types of care settings and care providers who provide services to this population.

4. Rate setting is particularly challenging for the disabled population because of the volatility of health status and the unique special needs that are often present.

5. Managed care organizations, because of liability and risk management issues, may feel that they need to credential and certify providers, thereby over-medicalizing services that are provided by friends or families.

6. Disabled individuals often have long standing relationships with certain providers, many of whom may have been providing care for years. If the disabled individual is required to change providers, the impact could be disruptive to the care plan and demoralizing for the member.

There are also positive opportunities for managed care and the disabled population:

1. If the disabled population represents the last bastion of fee-for-service medicine and reimbursement declines, this population runs the risk of decreased access to health care services and programs and the possibly of the creation a two-tiered system, one for the disabled, and one for everyone else.

2. Managed care, through its purchasing power, can reduce the cost of certain services or drugs needed by the disabled person.

3. Managed care can act as an advocate for the disabled member, ensuring access to quality services.

4. Managed care, through its credentialed network, can measure quality outcomes on behalf of the member.

I have tried to list both the opportunities and the challenges of enrolling the disabled population into managed care. In numerous conversations I had with disabled individuals and advocates in preparation for this testimony, I have put together a list of recommendations for next steps:

1. Move slowly and deliberately with caution. We are not ready to go statewide, much less nationwide with moving the disabled into managed care. We should look at developing pilots and demonstrations and then evaluate their outcomes.

2. We must include the disabled in the design, implementation and evaluation process. My experience with many disabled individuals underscores the need to first look at what services are being delivered now, where can improvement be made, and how do we ensure that we measure the outcomes. Disabled people will tell you they know where dollars can be saved, but managed care must include them in this discussion.

3. We must develop a credible risk adjustment payment methology for this population. There is much talk about this for other government populations (i.e. Medicare and Medicaid) but nothing has been developed so far.

4. Managed care will have to address some of its utilization controls and benefit limits. They may not be appropriate for a disabled population.

5. Managed care will also need to be aware of the concern by many in the disabled community about the over medicalizing of the personal care attendant model. Managed care will need to balance its risk management and quality assurance needs with the appropriate independence agenda of many disabled people.

6. Managed care organizations must build trust with disabled members. If a disabled person is mandated into joining an HMO, and they are unhappy or mistrustful, they run the risk of non-compliance or open defiance of care regimens.

7. Managed care must learn to contract with a new set of players who interact with and provide care for disabled people. Community based agencies, long term care facilities, personal care attendants, special home care and transportation agencies are just a few examples.

8. The service coordination role for this population will need to be discussed. Where does it reside? At the county, the state, a private agency, or the HMO? There are pros and cons to each approach. Perhaps we should test each model and decide which is best.

And finally...

9. The term managed care itself may be a problem. Many disabled individuals feel that they have "managed their care" quiet well and are unclear as to what value the managed care organization brings to the table. Managed care organizations will have to continue to educate people about the value they bring around network management, claims processing, credentialing providers, measuring quality, aggregating insurance risk, profiling physicians and service and product discounts, to name a few.

On behalf of my peers and colleagues in the disabled and managed care communities in Minnesota, I appreciate the opportunity to testify in front of the Senate Special Committee on Aging. I look forward to your comments and questions. Thank you.

BACKGROUND INFORMATION

PATRICIA A. RILEY
VICE PRESIDENT, GOVERNMENT PROGRAMS
ALLINA HEALTH SYSTEM
MINNEAPOLIS, MN

REPRINTED WITH PERMISSION FROM

FAULKNER & GRAY, INC.

CHAPTER 8

Communicating With Vulnerable Populations: Medicaid

Holly Ross and Katherine Cairns

Moua,* a 37-year-old pregnant Hmong woman, lived with her seven young children in a cramped apartment in Minneapolis MN. The family survived on AFDC (Aid to Families with Dependent Children) funds and received health care through Medica Choice Care, the Medicaid managed health plan offered in Minnesota by Allina Health System. From the beginning, Moua's pregnancy had been identified by her health care providers as a high-risk one, and by her seventh month she was experiencing vaginal bleeding. To help ensure that her pregnancy would go full term—and that the baby would be born healthy—Moua's doctor ordered partial bed rest. But how could she, a mother of seven young children with no adult relatives to help her and no money for babysitters, stay off her feet for more than a few minutes at a time?

The prenatal nurse who worked with Moua's doctor called one of Medica Health Plan's special prenatal care coordinators. Together, they arranged respite child care for Moua with a local nonprofit agency. Every day, from 2 p.m. to 10 p.m., Moua's three youngest children were cared for while she rested in bed. The care coordinator also enlisted the help of a Medica Health Plan social worker, who, accompanied by a Hmong interpreter, visited Moua several times to assess her other needs. The social worker noticed, for example, that Moua had no crib for the new baby, so she arranged to get her one. The social worker even brought the crib to Moua's apartment herself and helped the family set it up.

All these efforts helped. Moua had a full-term pregnancy and delivered an eight-pound, seven-ounce healthy baby girl. Both mother and child have remained healthy.

Sasha,* a 54-year-old recent immigrant from Russia who spoke little English, had been suffering from a tooth ache for several days. Finally, the pain became so great, he decided to see a dentist. He remembered that someone from Medica Choice Care had called and spoken to him—in Russian—about the plan's dental services. He called the special phone number that had been given to him and immediately found himself talking with a Russian-speaking access representative at Medica Health Plans. Not only did the representative help

---

* Names changed to protect privacy.

Sasha make an appointment with a dentist, he also arranged for Sasha to have free transportation service to and from the dentist's office and for a Russian-speaking interpreter to meet him there so Sasha and the dentist could effectively communicate with each other.

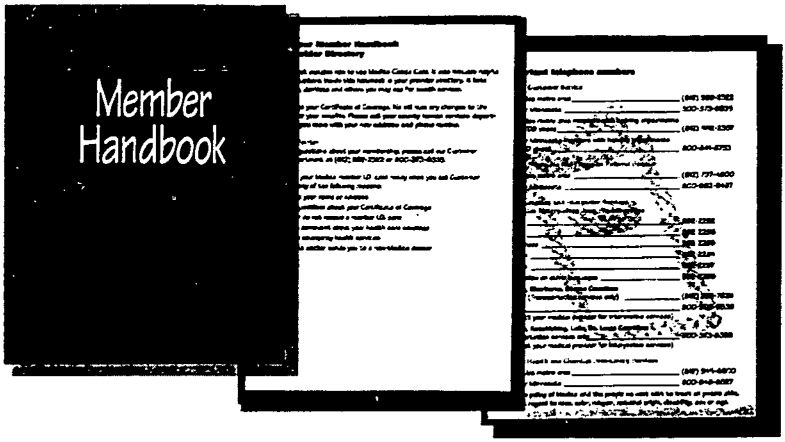
For Moua, Sasha, and many other Medicaid recipients, having health care coverage does not necessarily mean having access to health care services. Nor does it mean being able to follow a doctor's prescriptions for getting or staying healthy. Medicaid recipients are, by definition, people with low incomes, which means they often have pressing social needs—such as finding housing or keeping a telephone connected—that take precedence over getting health care, especially preventive care. Indeed, because of a lack of affordable transportation, many Medicaid recipients have trouble just *getting* to a doctor or dentist. And even when they do make it to the office of a health care provider, Medicaid recipients often face language or cultural barriers that make it difficult for them to understand what the provider is advising them to do about their illness.

As Minnesota's largest provider of Medicaid managed care, Medica Health Plans understands that serving low-income populations requires more than simply providing quality health care services. If a managed care system is going to be truly effective in helping low-income people lead healthier lives, it must address their social concerns as well as their medical ones. That's not to say that Medica or any other managed care organization can take on all the social and public health problems of its Medicaid enrollees. But if the social problems of Medicaid members are not considered *at all*, those members are likely to get lost in the complexity of the health care system and will not get the medical care they need.

In recent years, Medica Health Plans has played a leading role in identifying the obstacles that Minnesota's vulnerable populations face in accessing health care. It has also been a leader in developing and implementing innovative ways of enabling people to overcome those obstacles. These efforts have presented the company with a variety of often daunting communication challenges. For example, how do you effectively present information to a group of people who understand little or no English, but who individually speak more than 100 different languages? How do you educate people about the need for preventive medicine when they are struggling with poverty, family violence, hunger, and homelessness? How do you send health care messages to people who have no telephone nor even a permanent address? How do you explain to people what their health benefits are when they have just immigrated from a culture where medical treatment consisted of herbs and spells dispensed by a village shaman?

Meeting these communications challenges requires managed care organizations to think in creative, nontraditional ways. The standard communications methods used to reach health plan enrollees—newsletters, informational packets, customer service phone lines—are frequently ineffective with more vulnerable populations. So although Medicaid recipients must be treated the same as other health plan enrollees in terms of the quality of care they receive, their very special needs require new and innovative methods of communication. Indeed, with vulnerable populations, communication takes on a much broader definition. It includes, for example, such nontraditional tasks as arranging for foreign language interpreters, keeping a pregnant woman's phone service from being disconnected so her prenatal nurse can keep in touch with her, or helping a woman find shelter from an abusive spouse. All of these actions, however, have the same central focus: making it easier for Medicaid recipients to access medical care.

Although Medica Health Plans' efforts in reaching and helping its Medicaid enrollees are by no means complete, it has already experienced some major successes. In fact, a recent independent survey of thousands of Minnesota's health care consumers found that Medicaid recipients in managed care plans are *the* most satisfied health care consumers on Medicaid in the state.



Source: Medica Health Plans.

MEDICAID IN MINNESOTA

Minnesota was ahead of most states in enrolling people on Medicaid in managed care plans, which is why Allina Health System—through its health plan, Medica Health Plans—has a longer history serving Medicaid recipients than many other HMOs around the country. Minnesota's Medicaid program, referred to as the Medical Assistance Program, or MA, is administered through the state's Department of Human Services. From 1965, when the Medicaid program was first enacted, until 1985, Minnesota, like other states, administered MA only through a fee-for-service system, except for a few, very small voluntary managed care options. Under the fee-for-service system, an MA recipient obtains care from a medical provider, who then submits a claim to the state for direct reimbursement.

In 1985, however, Minnesota became one of the first states to contract with HMOs and other managed care plans to enroll MA recipients on a mandatory basis. It did so under a program originally referred to as the Minnesota Prepaid Medicaid Demonstration Project, which was one of the original five demonstration projects authorized by the U.S. Health Care Financing Administration, the federal Medicare/Medicaid agency. The program, now known as the Minnesota Prepaid Medical Assistance Program (PMAP), is a prepaid, capitated managed care program. It currently operates in sixteen Minnesota counties, and state officials plan to expand it into all areas of the state within the next few years. Under this program, MA recipients obtain care from their health plan providers, who submit claims to the health plan rather than to the state for payment. Contracting health plans are prepaid capitation amounts from the state each month to cover MA-covered services for enrolled members. Thus, the health plan carries the financial risk for the health care provided to each MA member. If health care costs exceed the capitation payment, it's the health plan that bears the loss. Of course, the reverse is also true: if the costs are less than the payment, the health plan reaps the gain.

Minnesota's motivation for contracting on a mandatory basis with managed care plans was threefold: affordability, accountability, and accessibility. State legislators wanted not only to keep Medicaid costs under control, but also to ensure that the health care received by the state's Medicaid beneficiaries was accessible and of a consistent quality. Even at that time, managed care was a very common option in Minnesota's private sector, particularly in the Twin Cities metropolitan area, so contracting with HMOs to enroll MA recipients was not the big leap that it was in other states where managed care was not so prevalent.

Although it has had its share of bumps and glitches, PMAP is generally viewed as being very successful in Minnesota, which is why the state has continued to expand the program. Today, as a condition of licensure and in order to participate in other state-funded programs, such as workers' compensation, HMOs operating in Minnesota are required to contract with the state to enroll MA recipients. Furthermore, each HMO must be willing to enroll a proportion of the market share of recipients based on a formula specified in law which factors in private market share within a particular geographical area. Under PMAP, a participating health plan must cover all medically-necessary Medicaid-covered services, including the medical, dental, mental health, and home care needs of its MA recipients. It is not required to provide the room and board costs for people living in nursing homes or in group homes for the mentally disabled. Those costs are covered by the state outside of the capitation payments.

MEDICA HEALTH PLANS AND MEDICAID

Medica Health Plans, part of Allina Health System, is a direct descendent of Physicians Health Plan—one of the eight initial prepaid health plans that Minnesota contracted with in 1985 for its PMAP. Thus, Medica Health Plans, through a direct predecessor, has been a consistent participant in Minnesota's managed care Medicaid program from its inception.

PMAP began as a relatively small demonstration project. Originally, only three counties participated: Dakota, a generally suburban county; Itasca, a rural county; and Hennepin County, home to the city of Minneapolis. However, Hennepin, which has more than half—74,000—of the state's MA recipients, did not come fully into the program until 1991. Although it was clear from PMAP's onset that Medicaid recipients had specific health care needs, as the program grew—especially after Hennepin County came fully into it—those needs became further clarified. As the program evolved it also became increasingly clear that meeting the needs of Medicaid recipients would require an entirely new and creative approach to the delivery of health care, which, in turn, would require new methods of communication.

A NEED FOR A REEVALUATION

By the early 1990s, Medica noticed a troubling trend reported by its providers: Medicaid members had a very high—about 45 percent—no-show rate for doctor appointments. Many of Medica's providers were justifiably upset with such a high level of patients missing appointments, for it made the running of their practices more difficult. But the providers had an even greater concern: These no-shows meant that many Medicaid recipients were not receiving the health care they needed.

In 1992, the Medica Foundation (now the Allina Foundation) decided to look more closely at the health care needs of its Medicaid members. It commissioned a comprehensive study of Medicaid recipients in Minnesota's Hennepin and Dakota counties, two of the three original counties included in the PMAP demonstration project. The study looked at recipients who were enrolled in Medica Choice Care and two non-Medica managed care plans, Metropolitan Health Plan and UCare. During the entire study, which lasted from

June through November of 1992, more than 2,000 people, including Medicaid recipients and key people in the community who work with public-sector clients, were surveyed. To ensure detailed and accurate responses, three different questioning formats were used—mail, telephone, and face-to-face interviews. The survey presented a complex communication challenge, for the questions not only had to be translated into many different languages, they also had to be carefully constructed to ensure their meaning would be effectively understood across all cultures.

The study drew many conclusions, but two stand out. The first was that health-care coverage provided by managed care plans must reflect the great diversity of the Medicaid population. Medicaid recipients represent a wide cross-section of society with many subgroups that have unique needs and challenges. To serve all these varied needs, the study concluded, a health plan must take a specialized approach when developing programs for its Medicaid members. A "one-size-fits-all" approach simply will not work.

The second major conclusion of the study was that a successful managed care program for Medicaid members must integrate social services with traditional medical services. Medicaid recipients include many members of a highly vulnerable population with a wide range of social problems that invariably affect their health care—things like being evicted from an apartment, not having telephone service, or not having an affordable means of transportation to the doctor's office. A health plan cannot help its members receive quality care without helping them resolve these problems as well.

As a direct result of the study, Medica Health Plans decided it needed to look inward and reevaluate the structure of its Medicaid program and its overall approach to its members. In May of 1993, the company hired a fulltime director for its Medicaid Department. The director began to assemble a staff with expertise in managing the complex health and social needs of low-income people. The first goal: to find ways to eliminate the barriers that were preventing Medica Health Plans' Medicaid recipients from receiving appropriate health care. They decided to begin by tearing down the two biggest barriers: language and transportation. It soon became clear that the success of these efforts would require some innovative forms of communication.

OVERCOMING THE LANGUAGE BARRIER

When asked in the 1992 survey, "Do you need an interpreter when going to a medical doctor?" four distinct subgroups of Medicaid recipients overwhelmingly responded "yes." All Laotian respondents (100 percent) and a large majority of Hmong and Vietnamese respondents (96 and 89 percent, respectively) said they needed an interpreter in order to communicate with their physician. A smaller, but still significant, majority of Russian respondents (67 percent) also said they needed an interpreter in order to understand their doctor's diagnoses and instructions.

Nor are these the only groups of Medicaid enrollees with members who need an interpreter to talk with their doctors. Medica Health Plans has had requests for interpreters representing more than 100 languages, ranging from Finnish to Nuer, a Sudanese dialect.

To better communicate with and serve this diverse clientele, Medica Health Plans has hired multilingual access representatives for its Medica Choice Care members and initiated a program called Interpreter Services. As their job title suggests, the access representatives are responsible for helping Medica Choice Care members *access* their health care providers. The representatives provide a variety of services, from helping a member set up an appointment with a health care provider to arranging for a taxi or van to pick up and take the member to the provider's office.

These access representatives should not be confused with customer service representatives, who answer members' questions about their plan's benefits and coverage.

Medica Health Plans currently has customer service representatives assigned exclusively to its Medica Choice Care enrollees. Importantly, Medica Health Plans recently moved its Medicaid customer service representatives into the same work unit and physical space as its Medicaid access representatives so the two groups could work side-by-side and better coordinate their efforts. Some of the customer service representatives are also being cross-trained to serve as access representatives.

Allina's Medica Health Plans serve nearly one million members. They offer a broad range of self-funded and fully insured health plan products, including a Medicaid product, now known as Medica Choice Care.

Of Medica Health Plans' current Medicaid access representatives, several speak either Russian, Hmong, Spanish, or Vietnamese. These languages represent the four largest language subgroups (besides English) among Medica Health Plans' Medicaid population. Members can bypass Medica Health Plans' English-speaking customer service line and call a Russian-, Hmong-, Spanish-, or Vietnamese-speaking access representative directly when they have questions or need assistance. Special phone lines have been set up to handle these calls.

Medica Health Plans has also initiated a program called Interpreter Services for members who need an interpreter to go with them to a doctor's or dentist's office or to a mental health or chemical dependency treatment facility. A member in need of the service calls a Medica Health Plans access representative, who then arranges, through one of the interpreter agencies under contract with Medica Health Plans, to have an interpreter at the health provider's office when the member arrives for his or her appointment. The access representative also notifies the provider that an interpreter will be there.

Medica Health Plans set up its bilingual phone lines in 1994. It soon became clear, however, that hiring a bilingual staff, hooking up special phone lines, and having additional interpreters on-call were only the first steps. In order to get people to use these services, Medica Health Plans had to find an effective way of informing Medicaid members of their existence. But how do you get the word out to people who do not read or speak English, and, in some cases, do not read *any* language? Medica Health Plans found that the best way was by reaching out in person to each member. So, in addition to printing the phone numbers of the bilingual access representatives in every brochure and piece of informational literature sent to members, the State Public Programs staff made a strong effort to personally notify members of its foreign-language services. They called members to tell them about the services. They even set up displays at clinics serving large numbers of non-English-speaking clients at which they handed out wallet cards with the special bilingual numbers on them. Once one member began calling one of the special phone lines and using the services, he or she would usually pass on the number to relatives or friends. In the end, this word-of-mouth promotion proved to be the most effective way of getting the word out about Medica Health Plans' access services. Today, the access representatives handle about 70 foreign-language calls daily.

Medica Health Plans' State Public Programs staff has also made sure that all written material sent to Medicaid members have sections translated into the four main languages. Such translations appear prominently on the inside front cover of the member handbook, for example. In addition, *Living Smarter*, the quarterly magazine sent to every Medica Choice Care member, runs translations of informational articles about such topics as prenatal care and well-child checkups in every issue.

The translations seem to be appreciated and well-received, but no evaluation has yet been done to see if they are widely read. Finally, all magazine articles, brochures, and other materials sent to Medica Choice Care members are written at a seventh grade reading level to make them easier for people struggling with English to understand.

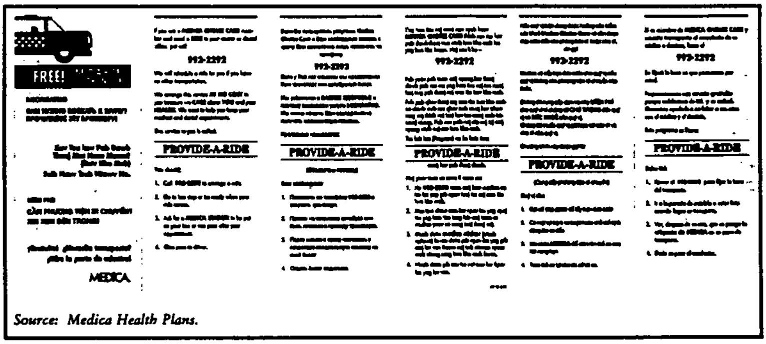
OVERCOMING THE TRANSPORTATION BARRIER

Among the respondents to the 1992 study, more than half said lack of transportation was a barrier to visiting the doctor. More than one-third said they had missed a medical appointment during the past year. In the Native American population, the percentage was even higher—two-thirds. Extrapolating these figures to Medica's entire Medicaid membership meant that the number of missed appointments during 1992 equaled almost 9,000.

Four in ten respondents cited transportation as the most common reason for missing an appointment, while two in ten said they had no one to watch their children while they went to the doctor, and another two in ten said they simply forgot. Other miscellaneous reasons were also cited, ranging from not being able to find the doctor's address to being "too sick."

Obviously, something needed to be done. Medicaid members could not receive the quality health care Medica's medical providers were offering if they could not get to those providers' offices. So when Minnesota offered HMOs $80,000 each to implement a project of their choice that would improve the state's Medicaid enrollees' access to health care, Medica Health Plans quickly jumped at the opportunity to launch what is now known as the Provide-A-Ride program, a free transportation service for Minnesota's Medicaid enrollees. The Medica Foundation (now the Allina Foundation) provided an additional $400,000 to cover the project's initial administrative and set-up costs.

Through Provide-a-Ride, which was the first transportation program of its kind in Minnesota, Medica Health Plans' Medicaid members are offered free taxi, van, or bus transportation to and from their health providers' offices. Members who need a ride call one of Medica Health Plans' access representatives, who arranges the transportation—after first checking in a computer database to make sure that the member has a current Medica Choice Care policy and that the doctor is under contract with Medica. If the person calling is not a member of Medica Choice Care, the access representative refers the caller to other transportation services or back to his or her county case worker.



Source: Medica Health Plans.

Before Provide-a-Ride was started, Medicaid members could get reimbursed for taxi or bus fare to their health care providers, but the process was not easy: the member would have to pay for the ride, keep the receipt, then turn it in to a county financial officer (along with a completed form) for reimbursement. Many Medicaid members did not have the cash to pay for a ride up front; others found the process of filling out and mailing the forms too daunting. The service, therefore, was seldom used. Provide-A-Ride removed those obstacles by setting up a system in which Medica Health Plans, not the Medicaid members, paid for the rides and then applied to the state for reimbursement.

Provide-a-Ride has proven to be a huge success. In 1995, the program gave more than 84,000 free rides to Medicaid members. Since the inception of the program, more than 174,000 rides have been provided. No-shows at some of Allina's clinics have decreased by 50 percent or more, which has made it very popular among providers. The state has continued to fund the program, although Medica Health Plans is now reimbursed on a capitated basis. This has reduced the paperwork involved, but has also placed the financial risk of the program squarely on Medica Health Plans' shoulders. Still, Medica Health Plans is committed to keeping Provide-a-Ride going because of the great benefits it offers not only to its members, who are now less likely to delay seeking health care, but also to its providers, who can now be more confident that a Medicaid patient will show up at the appointed time.

In an effort to keep costs down and prevent abuses of the program (most notably, the use of the taxis for nonmedical trips), Provide-A-Ride has undergone some revamping over the years. Documentation and auditing of member abuse of the transportation benefit has been strengthened.

Today, when a member calls requesting an immediate ride to a doctor or emergency room, the access representative sets up a three-way conference call between the member, the representative, and a registered nurse from Nurseline, Medica Health Plan's 24-hour telephone helpline. The nurse does an on-line triage, asking questions of the Medicaid member to determine whether his or her medical condition truly does require a trip to the emergency room. Unless needed to interpret, the access representative does not participate in this conversation, but simply stays on the line to call for transportation should it be necessary. More often than not, the situation turns out to not be an emergency, and the nurse, after reassuring the caller, recommends that the member make an appointment with his or her doctor. The access representative—who is still on the line—then takes over to help the member arrange the appointment and transportation.

Medica Health Plans has found that cultural differences play a big part in why some Medicaid recipients don't make appointments with doctors, but instead go straight to the nearest hospital emergency room when they or their children are ill. Hmong immigrants, for example, were accustomed in their villages to visiting a healer—without an appointment—when they felt ill and to wait in line all day, if necessary, to see him. The Hmong, therefore, looked upon the primary care clinic, or emergency room, as a healer's home—a place to go when you are ill and wait for care—frequently appearing early in the morning. Medica Health Plans' challenge has been to educate the Hmong—and others—about when to use clinics and hospital emergency rooms, and when to call a doctor. Once again, Medica Health Plans has found that the best method of doing this education is through one-on-one discussions.

WELCOME CALLS

To better communicate the breadth and availability of all its services to Medica Choice Care members, Medica Health Plans initiated a new member outreach program in 1995. Medica Health Plans' access representatives contact each new Medica Choice Care member either by phone or, if that is not possible, by letter, shortly after the member enrolls in the plan. (A letter is used only as a last resort; at least four attempts are made to contact new members by phone.) If possible, this welcoming contact is in the member's own native language.

Many health plans, of course, welcome new members. But Medica Health Plans' outreach program to Medica Choice Care members offers much more than a friendly hello and an explanation of benefits. Medica Health Plans views the welcoming call as an opportunity to immediately connect members to needed medical *and* social services. The representatives begin by telling the members about Medica Health Plans' free Medicaid services, such as Provide-a-Ride and Interpreter Services. Then they ask several basic health-related questions, such as "Are you pregnant?" or "Do you or one of your children have asthma?" If the member answers "yes" or "maybe" to one of these questions, the representative inquires further to make sure the person with the condition or illness is currently under the care of a health care provider.

The representative also asks members with children under the age of five if they participate in the WIC (Women with Infant Children) program, the federally-funded program that provides nutrition education and nutritious-food advice to low-income pregnant women and mothers with young children. If a member says "no," the representative sends a fax to the WIC program, which then makes sure one of its workers contacts the family to schedule an appointment.

During welcoming calls, Medica Health Plans' access representatives also inquire as to whether members have any clothing, housing, or other urgent social service needs. If a member indicates that he or she would like help with a particular problem, the representative passes that information on to one of Medica Health Plans' social workers. It's not unusual for a new member to have an urgent need for assistance. One young mother, for example, told the access representative who first contacted her that she and her two young children had been forced to move in with her sister after their house had burned down and now the sister was about to be evicted. The representative passed this information on to one of Medica Health Plans' staff social service coordinators, who immediately started helping the young mother get in touch with county agencies that could help her find emergency housing. During another call, a representative noticed that the new member answered "yes" very quietly when asked if she needed any resources about family violence. Realizing that the woman might be afraid to speak up because her abuser was in the room with her, the representative asked if she was safe at that moment. When he felt confident that the woman was not in immediate danger, he gave her the phone number of an Medica Health Plans social worker and told her to call the number when she felt free to talk about her options for getting help. The woman did call later and received the assistance she needed.

These welcome calls have been very well-received by members. Not only do they help educate new members about the health resources available to them, they also go a long way toward establishing a friendly partnership relationship between members and the Medica Choice Care staff. As one member said to an access representative when she realized what the phone call was about: "What! My health insurance company is actually calling me?" As a result of these personal contacts, members are less hesitant to call later with questions or concerns—and, as a result, more likely to get timely, appropriate health care.

OVERCOMING OTHER BARRIERS

Not being able to afford phone service can be a serious impediment to getting and following through on medical care. In the 1992 survey of Medicaid recipients, 30 percent of Native American respondents, 15 percent of African-American respondents, and 12 percent of Hispanic respondents said they were not able to make phone calls at home.

Medica Health Plans cannot, of course, afford the cost of supplying all its Medicaid members with phone service. But in very unusual situations, such as when a Medicaid recipient is experiencing a very high-risk pregnancy and her phone has been disconnected for lack of payment, Medica Health Plans arranges, usually through local social services agencies, to have the phone reconnected so she can stay in touch with her health care provider. Appropriate repayment plans are implemented along with long distance and collect call blocks on the phone line.

Finding a safe place to leave their children while they go to a doctor is also an obstacle for many Medicaid recipients. In the 1992 survey, about half the members said they take their children along on doctor visits. The second most common alternative to child care was leaving them with a friend. The third most common was leaving them home alone.

To help its members overcome this obstacle, Medica Health Plans makes a point of seeking to contract with health care providers who have play spaces and/or child care personnel on site at their offices and clinics. For many Medicaid mothers, knowing that a clinic is "child-friendly" has made a big difference in getting them to keep their medical appointments. In very rare cases, usually involving high-risk pregnant women who have been prescribed bed rest by their physician, Medica Health Plans has arranged and paid for a limited amount of child care.

OVERCOMING BROADER BARRIERS: SOCIAL SERVICE COORDINATORS

Medica Health Plans believes strongly that enhancing access to care for low-income and special-needs populations requires an integration of social and medical services. People who are worried about being evicted from their apartment, who do not have sufficient food or warm clothes for their children, or who are wondering how they are going to pay their electric bill and keep their lights from being shut off, are unlikely to have the time, energy, or money to seek or follow through on medical care, even when they desperately need it. In addition, the unrelenting stress of living with poverty can often trigger or aggravate a medical condition.

To help meet the social service needs of its low-income members, Medica Health Plans' State Public Programs department took the unusual step of hiring social service coordinators in 1994. The coordinators help link Medica Health Plans' Medicaid members with community resources. Sometimes they do this by working directly with a member, either over the phone or in person; other times, the social service coordinators simply supply information about community resources to a member's health care provider, who passes it on to the member at an appointment.

The specific jobs performed by the social service coordinators are as varied as the individuals who are referred to them for help. Medica Health Plans' coordinators have done everything from helping a first-time mother buy clothes and equipment for her newborn infant to aiding a destitute family in its search for livable housing to accompanying a woman as she sought a restraining order against her abusive husband.

Such efforts can have a substantial effect on the health of a Medica Choice Care member. In the case of Lisa,* for example, the actions of a Medica Health Plans social service coordinator may have prevented a premature birth. Lisa, a young pregnant woman with no family support, had a low-paying job—so low that she qualified for Minnesota's Medical Assistance. During the twentieth week of her pregnancy, Lisa went into premature labor. Her physician was able to stop the labor from progressing but told Lisa she would have to remain in bed for the remainder of her pregnancy. Lisa quit her job. Unable to keep up with her bills, she soon found herself without a phone, and with a warning letter that her electricity was about to be shut off, and an eviction notice from her landlord. Yet because of the doctor's orders, she was too frightened to leave her home and apply for public assistance.

At this point, a nurse who had been checking on Lisa notified a Medica Health Plans social service coordinator of the seriousness of the young woman's living conditions. The coordinator went to work immediately on Lisa's behalf. She called local community organizations with the resources to help keep Lisa from getting evicted or having her electricity shut off. She also arranged for Lisa's phone to be reconnected. The coordinator then went down to the local AFDC offices and filled out all the necessary forms so Lisa could start receiving the financial benefits for which she qualified.

The stress in Lisa's life diminished dramatically. In fact, at her next pregnancy check-up, her doctor said he couldn't believe the change for the better in her physical condition. Lisa remained at home for the rest of her pregnancy, giving birth to a healthy nine-pound baby boy.

Without the assistance of a Medica Health Plans social worker, Lisa's difficulties might have taken longer to resolve, which might have resulted in a less favorable outcome for her pregnancy and a high cost hospital stay for a premature infant. Fortunately, the nurse working with Lisa's health care provider not only recognized the seriousness of Lisa's situation, but knew to call Medica Health Plans' social service coordinators for help.

REACHING OUT TO WOMEN WITH HIGH-RISK PREGNANCIES

In April 1995, Medica Health Plans launched a one-year study to see if offering social services as well as medical services to low-income pregnant women with very high-risk pregnancies could have a positive influence on the outcome of their pregnancies. For the study, which was named the Prenatal Trend Control Project, Medica Health Plans selected 351 pregnant women with very high-risk pregnancies from new enrollees in its Medica Choice Care (Medicaid) health plan—women who were under the age of 18, for example, or who had gestational diabetes, or who were living in a homeless shelter.

The project has staff who call each of the study's pregnant women regularly to ask them how they are doing. They work in conjunction with Medica Health Plans' social service coordinators and Trend Control prenatal nurses. If one of the pregnant women is having a medical problem, the prenatal coordinator passes that information on to a nurse. If the woman is having a social services problem—whether it be difficulty paying for a heating bill, getting out of an abusive relationship, or simply finding an affordable crib—the prenatal coordinator gathers that information and passes it on to one of Medica Health Plans' social service coordinators.

Women who have only a few needs may be called by a prenatal coordinator only once a month while those with significant difficulties may be called every week. If a woman smokes, she is contacted at least every other week to help her stop smoking.

How much of an impact such efforts will have on the outcome of the women's pregnancies will not be known until late in 1996 when all the enrolled women's babies have been born and Medica Health Plans' experts have analyzed the financial, birth, and pediatric outcome data collected during the study.

CREATING COMMUNITY PARTNERSHIPS

Many of Medica Health Plans' innovative programs for Medicaid recipients had their beginnings in Medica, the managed care company that merged in 1994 with HealthSpan, a health care delivery system, to form Allina Health System.

With the merger, however, came even broader opportunities to reach out to Minnesota's vulnerable populations. Many exciting new projects have been developed as a result.

Allina believes strongly that it must work in partnership with community groups to understand more clearly the barriers to quality care for low-income people and what can be done to remove those barriers. As Gordon Sprenger, Allina's executive officer, told members of the American Hospital Association when he became chairman of that organization early in 1996, hospitals and other health care organizations must not only help the ill and injured, but must also work side-by-side with communities and social service agencies to keep people healthy. Sprenger used an analogy heard frequently at Allina. "We're good at saving people after they have fallen from the boat and have been swept downstream," he said, "but unless we journey up the river and find out why they've fallen out of the boat in the first place, we will never have enough resources to save everyone who is struggling downstream."

Going upstream means taking on some tough and complex issues, things like the lack of affordable low-income housing and the spread of violence. "But in this new era of severely constrained financial resources, the only way to deal with some health care issues will be to solve some of our social problems," Sprenger added. "I urge us to engage ourselves with our communities to address violence, problems of youth unemployment, and housing with the same vigor we attack illness."

WORKING WITH INDIVIDUAL COMMUNITIES

Allina is currently sponsoring several community health improvement projects in low-income neighborhoods where many of its Medica Choice Care members live. Of course, such efforts are not new—many HMOs sponsor community projects. Indeed, integrated systems are at an advantage when it comes to developing such efforts because they can address the full spectrum of care, from health plan through care delivery.

Allina, however, is truly working to put the "community" into health improvement. Rather than initiating more "top-down" projects in which "experts" come into a community and essentially tell residents what needs to be done to improve their health, Allina starts with the premise that neighborhood residents themselves, not outside institutions, should be in charge of shaping the health of their communities. It's a radical new concept, and one that promises to have a real impact on the quality of life of many of the communities served by Allina.

One of those communities is Powderhorn, a diverse, urban neighborhood located in the heart of Minneapolis. Like so many other inner-city communities, Powderhorn has a large proportion of families living below the poverty level (more than 40 percent in some sections), an infant mortality rate of 13.5 per 1,000 (compared to the current national average of 7.7 per 1,000), and a high percentage of pregnant women (almost half) who receive no care during their first trimester.

In 1994, the Allina Foundation funded a two-year experimental project known as Healthy Powderhorn, with the stated goal of transferring leadership, ownership, and funding of the community's health concerns to its residents. The project broadens the definition of "health" to include adequate housing, job development, public safety, and personal development.

As part of the Healthy Powderhorn project, neighborhood residents have formed Citizen Health Action Teams (CHATs), each with its own agenda and action plans. Only residents and health care practitioners working in Powderhorn, including acupuncturists and other complementary practitioners, can serve on a CHAT. Allina provides funding and support staff.

Powderhorn's CHATs meet regularly to develop strategies for improving a particular health problem in the neighborhood, whether it be asthma in children or teen pregnancy or domestic abuse. The CHATs' action plans are often remarkably creative—and simple. One CHAT, for example, organized a walking group for adults. Twice a week, the group hikes the paths of the neighborhood's large park.

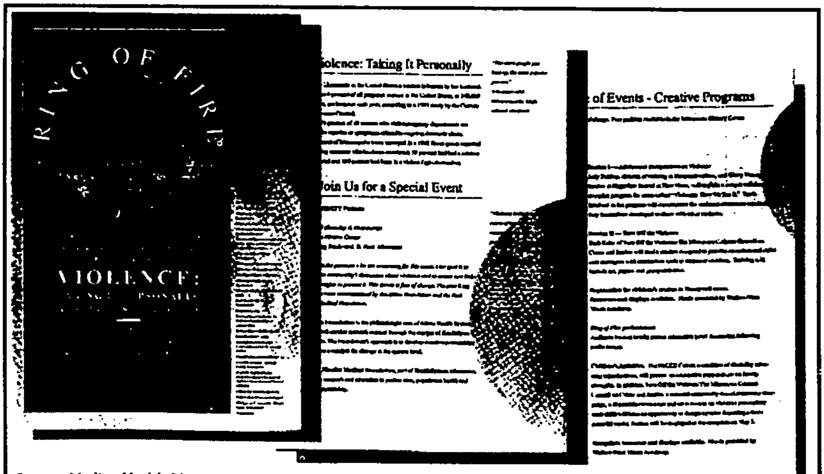
These outings not only help keep the walkers physically fit, they also help establish a strong adult presence in an area often used as a hang-out for disorderly youths. The CHAT members reasoned that a safer neighborhood was a healthier one.

It's not yet known how much of an impact Healthy Powderhorn has had on the health of Powderhorn residents. But both Allina and the Powderhorn community remain enthusiastic about the project's promise. As the project's citizen-designed brochure notes, Healthy Powderhorn offers a new and bold approach to improving community health: "Healthy Powderhorn recognizes that citizens wanting to achieve a healthy community need to find ways to improve the quality of life indicators that influence health. These include education, job satisfaction, safe homes and streets, air and water quality, and spiritual well-being. To achieve this, their scope must be much broader than the disease- and sickness-oriented medical system, and they must consider how to make health and wellness an integral part of everyday living."

WORKING WITH THE BROADER COMMUNITY

In addition to developing programs like Healthy Powderhorn that target specific geographic or demographic communities, Allina has developed a number of policies and creative projects that attempt to deal more broadly with the societal problems that impact individuals' health. As one element of its communication strategy, for example, Allina has developed a policy of not advertising on television programs that depict physical violence.

One of Allina's major communitywide projects is the Allina Violence Initiative, a health initiative designed to raise public awareness of such issues as domestic abuse, gun violence, and media-depicted violence. Allina believes strongly that projects like the Violence Initiative only work if done as a communitywide effort. In the spring of 1995, for example, Allina joined forty-nine community partners, including another health care system, in sponsoring a two-day forum on the role of the health community in violence prevention. Almost 1,000 people from 300 organizations, including educators, advocates for victims of domestic violence, and public health representatives, attended the widely-praised event. One of the forum's highlights was a performance by the nationally renowned Mixed Blood Theater troupe of *Ring of Fire*, a specially-commissioned dramatic play by the noted playwright Syl Jones. It offered a stark and often startling look at how violence affects the lives of individuals and communities.



Source: Medica Health Plans.

Dr. SCANLON. In this series of seminars, we have been looking at the issue of the readiness of managed care organizations and purchasers to use managed care as a means of providing health care for persons with special needs. In last week's seminar, I indicated that I thought there were four key components that were important in trying to assure that persons with special needs are adequately served by managed care organizations. I discussed three of those components then.

First was the issue of assuring that the managed care organizations have adequate networks of providers exists. In this instance, an adequate network of providers would include specialists and subspecialists that would be able to provide for the unique needs of the individuals in this population.

Second was the issue of rate setting. Rates need to be set in a way that does not compromise the ability of managed care plans to provide the services necessary for persons with special needs or discourages plans from enrolling. Third was appropriately defining the scope of coverage--recognizing that the needs of persons in this population can extend beyond the normal concept of medical necessity. Medical necessity in this context can include the need for services, not just for rehabilitation or to cure an illness, but to maintain one's existing level of functioning and health or to cope with the pain and discomfort associated with one's condition.

I would like to talk today about the fourth component -- accountability. The other three components dealt with issues that one might address before actually contracting with a managed care organization and enrolling individuals with special needs. Establishing accountability or quality assurance is a process that must be continuous and sufficient once plan contracts are signed and individuals enroll. Perhaps the key to quality assurance or accountability is information. It is not just critical for success with managed care for persons with special needs, but for other consumers as well. Managed care is a very large and undefined product. If we expect that individuals or group purchasers are going to be able to assess the quality of services that are being offered by managed

DISCUSSION

Ms. CHRISTENSEN. Don't they know their stuff?

If you have questions and have written them down, you can hold them up, and we will collect them, or if you just want to raise your hand, we can take those, too.

Yes.

QUESTION. Question about a legislative proposal.

Mr. SMITH. They excluded or exempted Medicaid from the ability of patients and physicians to decide on length of stay; is that correct?

QUESTION. Yes. [Inaudible.]

Ms. SMITH. Well, it will have a significant effect on the disabled population because so many of the disabled receive their health care through the Medicaid program. So in that sense, there is a disproportionate impact on them.

Obviously, it clearly sets up a different standard of care; you now have two standards of care operating, one for the Medicare program and one for the Medicaid program. Those are effects of those provisions. I cannot speak to what the motivation was. I would imagine that the fiscal concerns of the States played a part in that, but I cannot speak to what motivated it.

Mr. SCANLON. I am sure it was also consistent with the idea that part of the Medicaid changes are to grant States additional flexibility, and currently under the amount, duration and scope rules, States have had flexibility that might have been taken away by that provision, so it would be a step in the other direction.

Ms. CHRISTENSEN. I am going to go to a written question. This one is for Patsy Riley from someone from an advocacy group, about the social workers you employ as problem-solvers. Can you have a sufficient ratio to patient needs and still offer competitive rates?

Then there is a second question: Can you adequately access other public or private financing for housing, pre-employment services, and so on, to avoid failing to meet raised expectations?

Ms. RILEY. The first question I think relates to the staffing ratio of social workers to the number of enrollees we have. Let me just back up and say that our social work model is not typical of what you would see, for instance, in a county social worker kind of model. They are not there to provide continuous and ongoing social work support services for this population around their other kinds of housing needs and those kinds of things, but rather to troubleshoot and try to solve problems that are in the way of their getting medical services. So it is a different kind of model perhaps than what you are thinking of in terms of what a county social worker would do.

Up to this point, we have a staff of four who work in that area—and keep in mind our Medicaid population turns over quite a bit, so they are kept quite busy in terms of providing the kind of problem-solving activities that they engage in.

Your other question related to can we interact with or connect up with other kinds of agencies to maximize or perhaps leverage dollars that exist in other parts of the system. I think that some of the interesting demonstration projects that are now going to come out of this next round of trying to engage the disabled population in managed care in Minnesota will do exactly that. We are now going to look at three different county pilots where the county will probably be the purchaser of the services on behalf of the disabled population. This will be a very interesting demonstration project. They may contract with HMOs for some of the acute care services, but the counties are going to continue to do some of the contracting around the social services.

Ms. CHRISTENSEN. Thank you.

I have several questions here. The first one is for Bill and Barbara: What kinds of research or data are available that have aggregated costs across all public and private payment sources for an extended period of time, and for which special needs populations are these available?

Mr. SCANLON. Very little. One of the problems we have is that there are so many different financing sources for services, including individuals' families, that it has been very difficult to aggregate the information and be able to establish a clear picture for any one segment of the population with special needs, let alone the whole population.

We have surveys that have collected information and have emphasized the medical care expenditures and to some degree some of the long-term care expenditures for supportive services, but they are by no means complete. There is nothing underway or planned to truly address this question because the task is just too formidable.

Ms. CHRISTENSEN. Here is another one for Bill. Which States are currently using risk corridors? Are these initiatives successful, and are risk corridors likely to become more widespread?

Mr. SCANLON. There are five States that we identified that have risk corridors. I think Massachusetts and Wisconsin were two of them. In terms of their success, we have not really had the evaluation that would allow us to address the change in behavior or outcome associated with having a risk corridor versus not.

As I mentioned, when we did our review a year ago, the longest-running program in terms of mandatory enrollment was a little over 3 years old, and there was one program like that. The rest were much newer. Again, the impact may be a subtle impact, but difficult to measure. I am not aware of the evaluation that would focus on net aspects of the program design as opposed to the rest of the program design. They are interested now in the broad question of what difference does it make to have people with special needs in managed care versus having them in the fee-for-service sector, It is difficult to evaluate the details of the managed care arrangements.

Ms. CHRISTENSEN. I just wanted to mention that Bill has mentioned a couple of times a study they did last year, which we did not get up here today. It is a GAO report from last summer on people with disabilities and Medicaid managed care. We are also out of the GAO reports that we had on the table today, but if you want any of the materials that we have run out of, please let us know, indicate by your name or leave us a note, and we will be happy to send that stuff to you.

Question.

QUESTION. The risk corridor seems to be complex. Could you elaborate on that a little?

Mr. SCANLON. Sure. It is an effort to limit both the profits and the losses that a plan will face in serving beneficiaries. You can do it either on an individual basis or in the aggregate for a whole group of beneficiaries.

Most of the time, both the losses and the profit-sharing arrangements are graduated, so that within a small corridor, say a 5 percent profit or 5 percent loss, maybe the plan will be fully responsible or be able to fully retain the profit. So that as you move on, say, in the range of between 5 and 10 percent profit or loss, there may be some kind of sharing arrangement where the State will start to either take back some of the profit or provide additional revenues. As you keep moving farther out, the State share becomes even bigger.

This protects the plan that has had adverse selection and very expensive cases because they know they are going to be getting additional revenue as they have discovered that they now have those expensive cases, as well as a plan, in terms of setting their procedures and policies for providing services, understands that every dollar that you save on services is not a dollar of profit. There is going to be some limit on the profit.

One of the important things that is different about risk corridors from simple reinsurance is that the plans know in advance, so in terms of setting up arrangements with their providers, contracts for putting providers at risk, they know there are going to be some limits on the profits, and they can perhaps translate that into how they deal with the contracts for their providers.

I have found the page with the States that had risk corridors when we did our review. They were the District of Columbia, which had a small program for children; Massachusetts, Ohio, Utah and Wisconsin.

Ms. CHRISTENSEN. This question is for any of the panelists: Discuss the value of existing data from the SHMO, the social HMO, the PACE Demonstration and the PMAP program in establishing risk adjusters for the elderly.

Is there a comment on that?

Ms. SMITH. I think the PACE programs and the social HMOs and those kinds of things have been fairly small programs, and I am not sure that the data that has come in from those programs, which are very confined demonstrations, has really been tested by broad application. I guess that would be the best way to put that.

Mr. SCANLON. There is also an issue of self-selection, in that people were joining those programs because they found the particular benefits of those programs attractive. For example, the PACE program, which often has as its core an adult day care service. Adult day care has to be a service that is suitable for your needs, and you find it a valuable service to avail yourself of. That limits the generalizabilitiy of the data from these programs for generalized risk adjustment.

The other thing is that while the evaluations of both programs have provided rich data, the administrative problem in terms of doing risk adjustment for an ongoing program and having data available means that having rich data is not necessarily a good thing, because you will have variables that are excellent in predicting someone's health service needs, but it can be very impractical to try to collect those same variables for the entire population.

QUESTION. [Inaudible.]

Mr. RILEY. Medica is the only non-gatekeeper model doing Medicaid in Minnesota. All the other HMOs that do this are—some of them are closed panels, almost staff models—but all of them are gatekeeper models with the exception of ourselves.

We do not look at capitating or paying in any kind of way that would look like a risk-sharing arrangement with specialists for this population. Keep in mind that we are not doing the disabled right now; what we are doing is enrolling the AFDC population and the elderly.

On the elderly side—and back to the earlier question about PACE and SHMO—our State is now engaging in a demonstration around—we have never seen a demonstration that we don't like in Minnesota, by the way, so we will demonstrate anything—and now we are demonstrating sort of in between a SHMO and a PACE demonstration for our existing dual-eligible populations in Minnesota, and we have 5,000 of those. Half of Hennepin County's population residing in nursing homes are my members, so we have a big stake in whether or not the question relating to does the risk adjustment or the rate methodology that they have put together for this population—we are going to be paid under the PACE payment methodology, so invite me back next year, and I will tell you if it works—we have not started yet.

Ms. SMITH. There are a few contracts that specifically provide that people with certain types of conditions be allowed to use specialists as primary care providers. In general, I have to say that I cannot be called upon to say what does Utah do about this and what does Kansas do about that, but I do know that Massachusetts in particular has a very elaborate contract specification on network requirements for disabled populations, and the access that those disabled populations have to have to specialists, and they specifically delineate using specialists as primary care providers as one of the requirements, and that a plan has got to be able to demonstrate that they are doing that; and there are all kinds of performance measures along that as part of this quality evaluation in order to get renewal.

Ms. CHRISTENSEN. Go ahead.

QUESTION. [Inaudible] for 58,000 SSI, disabled and elderly recipients, integrating acute and long-term care. In addition, [inaudible], reconciliation bill, the States under flexibility will be allowed to do mandatory enrollment for all Medicaid recipients except SSI children, who are accepted, as long as [inaudible]. Given that States see lots of money being spent disproportionately on these populations compared with the AFDC populations, what recommendations would all of you have for those of us who are working on reconciliation to get some safeguards into the language or to advise HCFA on what ought to be looked at as States are doing this [inaudible]?

Ms. CHRISTENSEN. Could somebody summarize the question, too, for the mike?

Ms. RILEY. I think that what you are looking for is recommendations either to the reconciliation process that is going on right now or to HCFA, some of the recommendations that we have talked about here, around enrolling these populations into managed care. I just want to start out by saying that I hope I don't leave people with the impression of pessimism, because I believe that this is absolutely where we are going to end up.

What I would like to urge is caution and carefulness and thoughtfulness and engaging the population that we are talking about bringing into managed care, because they have strong opinions about how it should look. So that is kind of how I want to leave it with this group in terms of caution rather than pessimism.

Ms. SMITH. I think I would echo that. I think that as we have indicated, potentially, down the road, managed care offers a tremendous opportunity to this population for continuity of care and coordination of care.

I think the concern is that the political imperatives to change the system quickly may not accurately reflect what is happening in the marketplace right now in terms of the infrastructure that is being developed, the ability of plans to deal with providers that they are not accustomed to dealing with and create different types of networks.

Again, I use my analogy of Venus springing full-grown from Zeus' head. There are some political imperatives to have that happen, and it does not work that well on the ground in the delivery system. I think that if you are looking for protections, again, the protections would need to revolve around issues of access to care, quality measurement, network composition, accountability in terms of adequate protections around prior authorization and grievances, so that if people are being denied care, they have expedited channels to have those denials reviewed.

Mr. SCANLON. I would agree with Barbara. I think one of our problems, though, is that we are not ready—we have not achieved any consensus in terms of how to go about defining an adequate network, setting up what is considered an adequate grievance process. I think that in light of that, then, this may be appropriate for HCFA to think about, the issue of guidelines for the States so that we recognize that this is going to be an evolutionary process in which some of the State experimentation with variants of different approaches will actually be valuable in guiding us to better solutions.

One of the keys, though, that I think we need to focus on is that it is critical to have information about the services that are being delivered as well as, to the extent we can, the outcomes of services. Today, we are very often focused on outcomes as what should be the gold standard for deciding whether or not a plan is adequate. Yet, we are not at the point at which we know the range of outcomes that we should be measuring or even how to go about measuring some of the things that we know that we should be measuring.

We do need to be concerned about just the services that are being provided, and I think that one of the areas that we have an opportunity now to focus on is the question of encounter data. Information systems are being developed. They are expensive to develop.

If we develop them now around existing measures, we are going to come back in 5 years, when we have conceptually better measures, and say, gee, it is too expensive to implement those.

We need to think about information systems today that are flexible enough in providing encounter information that they will support the better conceptual measures that we have in the future.

Ms. SMITH. If I could just elaborate on one point in terms of the lack of consensus about what are the key performance measures, what are the standard procedures, one of the recommendations of the study that we did was that there needs to be a forum where the different players—the States, the consumers, and the providers come together and attempt to come to some consensus about what kinds of measures and standards work best in this environment, at least in the preliminary stage, so that we will then know what to measure.

Ms. CHRISTENSEN. Funny you should all mention guidelines and standards. Senator Grassley has an amendment in the Finance Committee bill requiring HCFA to pull together a group to develop some guidelines and standards for people with special needs being served by managed care plans, and we are very, very hopeful that it makes it through reconciliation, looking at a lot of the issues that have been talked about today—the medical necessity definition, the risk adjustment, the adequacy of provider networks and all those kinds of issues. So I think we are all talking about the same kinds of needs here.

Related to the question of mandatory managed care, somebody asks, Isn't it true that it's difficult to compute cost savings for managed care in the long run, so that if the incentive is to go into managed care for folks because they are high-cost folks, can we really compute any cost savings?

Anybody.

Mr. SCANLON. Well, we are questioning today whether or not there are cost savings for managed care in the longer term because we have limited experience with managed care for different populations as well as on a broad scale.

There are some that are responding to the notion that some of the slowdown in health spending that we have seen is really not cost savings that are going to continue over time, but a substitution, that we have substituted managed care for the fee-for-service provision of care.

Managed care is effective in terms of eliminating some of the unnecessary services. It is effective in terms of getting some discounts from providers. Now, when faced with new technologies that individuals want, will it be able to make judicious decisions that everybody is happy with? I think that that is the question that we are facing for the future, and that is what may determine the overall growth of costs for managed care in the future.

Ms. CHRISTENSEN. Are there any more questions?

QUESTION. Question regarding where the managed care industry is on a scale of 1–10 in the area of risk adjustment.

Ms. SMITH. I don't want to put the Medicaid agencies in a different position than the world at-large. I think that we are looking at risk adjustment being anywhere between about a 1 and a 2½. I like the way you developing put it in the continuum context rather than a judgmental context, but I think that we are really looking at that state of the continuum, and I don't think we have seen a lot of improvement in that in, say, the last 4 or 5 years. It has improved somewhat, but it has not improved hugely in that amount of time our ability to nail down a methodology.

There are things that you can do to compensate for the lack of risk adjustment. For example, a lot of States have stop-loss coverage, basically, for the plans—people that incur costs over $50,000, for example, the State will cover their costs in the fee-for-service system and will pay the plan on a fee-for-service basis.

So there are all kinds of things you can do to cushion the lack of an adequate risk adjuster, but I think that we are still looking at something which is relatively primitive in its development.

Mr. SCANLON. I would agree. I think there are two components here. One is the conceptual model that you use for risk adjustment, and while there has been progress made in that dimension, as Barbara indicated, it is there, but it has been relatively static for a while.

Certainly, I think there is the issue of the administration or the implementation of one of those conceptual models. But the conceptual models have been built off data that have been available to the existing fee-for-service system. We have not turned around and said how we will administer these models in a managed care environment, when the world is predominantly managed care. How is information going to flow well so that we can risk-adjust and additionally set rates in the future? Today, we are very happy setting managed care rates based on fee-for-service experience and saying, gee, we are doing well, we got a discount. What if we have predominantly managed care, and we don't have this fee-for-service benchmark anymore to guide us in terms of rate-setting?

Ms. CHRISTENSEN. One more question, and then we'll close.

Go ahead.

QUESTION. [Inaudible.] But I wonder how well we analyze the DRG system, which was [inaudible].

Mr. SCANLON. We don't want to wait until we have the perfect risk adjusters. We don't need the perfect risk adjusters to move forward. What we need to do is recognize the limitations of the risk adjusters we do have and to compensate for them appropriately.

The reinsurance, or what Barbara referred to as the stop-loss provisions, and the risk corridors that I talked about are ways of compensating for the lack of a good risk adjuster.

If you think about it, by using a pure capitation payment, you are betting that you were right in saying this is the amount we should pay. If you want to cover your bets and say we weren't necessarily right, we could be a little bit high, or we could be a little bit low, and you adopt reinsurance or a risk corridor, you have covered your bets in some respects.

The other thing to do is to be very sensitive about maintaining or continuing the process of learning, to make sure that you are collecting data to understand your experience, and you will be able to, in some respects, relax your reinsurance, relax your risk corridors in the future if you are able to better risk-adjust in the future.

I think those are the things you need to think about. We don't want anybody to leave here feeling like we should be paralyzed; we just need to be careful about how we make progress and do it in a deliberate and judicious fashion.

Ms. SMITH. Just to reinforce that, I think that what it really underscores is that we have to continue to make some R and D types of investments in developing the risk adjustment methodology, which we have really not done in a comprehensive way. That is going to be critical to the financial viability of a capitation approach.

The other aspect of it is that it means you have to continually monitor what your outlays are and how your various expenditures are going according to plans and then compared to your fee-for-service system, and this will be particularly important to the Medicare program where, right now, the Medicare program basically loses money on every person who enrolls in a managed care plan. Obviously, they are trying to turn that tanker around, but you have got to continually monitor the progress of that to make sure that you have in fact corrected it along the way.

QUESTION. Have you made any changes in terms of the kind of data that Medicare is going to be required to collect relative to these special needs populations? I mean, even now with the R and D [inaudible], so in 5 years, we'll have another [inaudible].

Ms. SMITH. Right.

Mr. SCANLON. We have not made good progress in terms of the data that Medicare is collecting on this population. In fact, a number of States are ahead of the Medicare program in that regard.

Ms. CHRISTENSEN. I wish we had time for all the questions that I have up here.

Thank you all for your time and preparation; it has been excellent.

Next week in this room, we will talk about quality in plans, and the week after that we will talk about the State contracting process.

Thank you very much.

[Whereupon the forum was concluded.]

QUALITY AND OUTCOME MEASURES

TUESDAY, JULY 15, 1997

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The forum met, pursuant to notice, at 9:30 a.m., in the Dirksen Senate Office Building. Ms. Susan Christensen, Public Policy Fellow, presiding.

OPENING STATEMENT OF MS. SUSAN CHRISTENSEN

Ms. CHRISTENSEN. We have arrived at our third forum in the series of four. The series is examining issues of managed care for people with special needs. So far, we have been very excited by the participation and the caliber of the discussion, and today should be no exception.

I learned a great deal just through the telephone conversations we engaged in to prepare for today's topic.

This series of forums came about after the Committee held a hearing about people with chronic conditions who are dually eligible for Medicaid and Medicare. We discovered that significant issues still need to be resolved when serving people with special needs in managed care plans. We divided those issues roughly into four main themes which are the topics of our four forums.

At the first forum, we got a picture of what it means to be a person with special needs. The theme of the second forum was the ability of the current managed care industry to deliver health care effectively to individuals who have a wide variety of specialized needs.

Today's forum covers quality and outcomes measures. We have devoted an entire forum to this topic because of its importance and because there is still so much to do in this area. The industry is only beginning to adopt patient-oriented standards for health plans that serve healthy people. Those measures rely on data, averages and indicators related to acute episodes from which enrollees are expected to recover.

That is not the situation with the beneficiaries who are the subject of our forums. Just as they need specialized and frequently long-term care, these beneficiaries will need specialized assurances of the quality of that care.

Our panelists will each make a short presentation; then we will have time for questions and discussion. Please jot down any questions that come to mind as you listen; Hope has some forms for you to use, and they will be collected at the end of the presentations when we have our discussion.

Our final forum will be next week. At that time, our panelists will discuss problems faced by States that want to contract to purchase managed care plans for their Medicaid beneficiaries with special needs. That forum will be next Tuesday in this room at 9:30 in the morning.

Ultimately, the Committee plans to publish the information generated by these forums and make it available to Congress and the public.

Once again, I need to thank LaVita Westbrook who is the organizer of all the details of these forums; without her, they would not happen.

Today our panelists are Bill Scanlon, who is Director of the Health Financing and Systems Issue Area at the U.S. General Accounting Office, GAO. He has been engaged in health services research since 1975. Before joining GAO in 1993, Dr. Scanlon was co-Director of the Center for Health Policy Studies and an associate professor in the Department of Family Medicine at Georgetown University. His research has focused in particular on the Medicare and Medicaid programs, especially provider payment policies, and the provision and financing of long-term care services.

We also have today Dr. Michael Collins, who is Deputy Executive Director at the Center for Health Program Development and Management at the University of Maryland Baltimore County. The Center is a health policy and information consulting firm within the State government. Dr. Collins's professional concentrations are in health care information and decision support systems, quality measurement, and program development and evaluation. He has worked with a wide variety of for-profit and nonprofit, private and public, U.S. and international organizations.

We also welcome John Ware. Dr. Ware is a Senior Scientist in The Health Institute at New England Medical Center and on the faculty at Tufts University School of Medicine and the Harvard School of Public Health. He is a member of the Institute of Medicine and serves on the board of directors of the Medical Outcomes Trust. Since 1984, Dr. Ware has served as principal investigator for the Medical Outcomes Study, which developed the SF–36 Health Survey and other tools widely used in monitoring outcomes for patients. Prior to joining The Health Institute in 1988, Dr. Ware was a senior research psychologist for 14 years at the RAND Corporation.

Finally, we welcome Trish MacTaggart. Ms. MacTaggart is the Director, Quality and Performance Management, Center for Medicaid and State Operations, in the newly reorganized Health Care Financing Administration, HCFA. She previously provided leadership in the development of Section 1115 waivers in the Office of State Health Reform Demonstrations at HCFA. Prior to coming to HCFA in March, Ms. MacTaggart was Director of the Medicaid program for Minnesota.

I am going to turn it over to Dr. Scanlon, and I believe the panel has decided amongst themselves what order they wish to go in, so I'll just let them take off. Each panelist will speak for about 5 or 10 minutes, and then we'll have questions.

[Note: Due to recording difficulties, it was not possible to make a transcript of the forum on Quality and Outcome Measures held July 15, 1997. Dr. Scanlon generously took the time to re-record his comments, which we are using to serve as a summary of the issues raised at the July 15 forum.

As part of its Violence Initiative, Allina also has partnered with the Minnesota Medical Association on its Stop the Media Violence campaign and with state officials in the creation of a new governor's commission that will look at violence as a public health issue. Through these and other collaborative efforts, Allina believes it can make an important and lasting contribution to the broad health of its communities, especially its more vulnerable ones.

CONCLUSION

Medicaid recipients are a diverse group of people with a variety of complex social as well as medical needs. The fact that Medicaid recipients have health care does not mean that they can *access* that care. Many Medicaid recipients face a host of obstacles—such as difficulty understanding English, finding affordable housing, or obtaining a ride to a doctor's office—that make it difficult, if not impossible, for them to keep appointments with health care providers or follow up on the treatment prescribed them.

For a managed care system to be effective, it must address the social as well as the medical problems of its Medicaid members. It must also develop innovative, nontraditional ways of communicating with those members. To be truly effective, however, all communication efforts must acknowledge the great diversity that exists within vulnerable populations. A one-size-fits-all approach does not work. As David Strand, president of Medica Health Plans and system vice president of Allina Health System, has said: "Health plans that truly serve Medicaid recipients must take a specialized approach and adapt to the distinct needs of low-income and special-needs enrollees. Such an approach presents those of us in managed care with both a challenge and an opportunity. The challenge is to listen more closely to what the enrollees themselves have to tell us about the obstacles that stand in their way to accessing quality health care. The opportunity is to work more diligently with them and others in our communities to help remove those obstacles. Only by listening well and working together will we enable our most vulnerable populations to receive the quality health care available to them."

care organizations, we need to know enough about services provided so that we can understand and evaluate plan performance. Information can play an essential part to counter the incentives for under-service that exist in the financial arrangements that define managed care, namely capitation, as well as to create real competition among plans on the basis of quality of service. That competition will ensure that individuals receive services that they need--and the best services possible--given the revenues available.

In today's marketplace, we are witnessing many larger purchasers seeking more information about services that managed care plans provide. In general, they are seeking information about population-based measures of the services provided to the individuals that they have enrolled in managed care organizations. To a more limited extent, they also are seeking information about the outcomes associated with those services. Certainly one of the most prominent examples of the movement to information collection for quality assurance is the Health Plan Employer Data Information Set, or HEDIS, which has been created by the National Committee for Quality Assurance, an organization of both purchasers and managed care plans. HEDIS is a series of measures that combines some structural characteristics--such as the turnover in a plan's network, the composition of a plan's beneficiary population, the plan's financial status--with process measures that identify the receipt of different services by individuals within the plan. HEDIS, while an extremely valuable step in the direction of collecting information about services received by individuals within a health care plan, focuses to a large extent on the general population, and not persons with special needs. The kinds of measures that are collected include items such as: immunizations, receipt of well childcare, and receipt of care for diabetes. It does not include the infrequently occurring types of conditions that we have been talking about in this series of seminars.

HEDIS is, however, a system, or a system that is continually in a state of evolution. Managed care organizations are now using HEDIS version 3.0 and efforts are underway to create the next version of HEDIS. I would anticipate that future versions will include a broader arrays of measures that will capture the services received by more narrowly defined segments of the population. It seems unlikely though that these future HEDIS measures will include many, or perhaps any, that relate specifically to the very low incidence complex conditions we have been discussing.

FACCT, or the Foundation for Accountability, represents a second prominent effort to identify information to measure plan performance. FACCT, which was established in 1995, is an organization of purchasers and consumers which represents the demand side of the healthcare market, as opposed to the NCQA, HEDIS's sponsor, which is more representative of the supply side. While FACCT attempts to focus on health care provided to consumers in the general population, as well as care provided to those with specific conditions, they focus on conditions that are more prevalent and that are thought to be of interest to a broader segment of the population. They also emphasize conditions where it is believed plans can make a difference in terms of improving health.

FACCT's approach involves selection of different clinical conditions--such as asthma, breast cancer, diabetes, or major depression--and then identification of a set of associated process and outcome measures. In these sets of measures, there are measures that reflect access to particular services. There is interest in including services that represent the state-of-the-art of care and services that represent good preventive care. There are also outcomes -- measures -- either intermediate outcomes such as the early detection of a disease, as well as survival rates for particular disease. Finally, there are measures of consumer satisfaction with the services that are being provided.

It is very easy to identify the shortcomings in the approaches that I have just outlined, relative to fully capturing the quality of services being provided to the general population of individuals that are enrolled in a managed care organization, and even more so for the care of the population of individuals with special needs. However, I think, in order to be fair, we need to recognize that these efforts are in their infancy. We only relatively recently have developed a considerable interest in assessing the services and the quality of services that managed care organizations are providing. There has been considerable evolution in the approaches, and progress continues to be made. Having said that, it is also important to think about the measures that we have available in the context of enrolling people who represent a highly vulnerable populations and making sure, that to the extent that these measures are not adequate, we take other steps to ensure that persons with special needs are adequately cared for by the managed care organizations with whom we contract.

It is important to recognize that we have only a handful of measures, and that we need to be concerned about the incentives that using these measures may create to "teach to the test". In other words, given that there are only a handful, fewer than 50, different aspects of care that are going to be monitored, it would be expected that a savvy organization would insure that it scored well on those dimensions. What was happening with other aspects of care would be unknown. Potentially, some other dimensions of care not being monitored, are not receiving adequate attention.

In terms of the future and the evolution of these approaches, adding more and more comprehensive measures is not an easy task. It is very difficult to decide what the norm for the receipt of care or an outcome should be. Furthermore, even when we decide that receipt of a particular treatment is the norm for a particular condition, we need to understand what the prevalence of need for that particular treatment is. In other words, we need to understand what the denominator is, or how many persons should receive that service -- in order to be able to identify whether or not enough of that service has been provided. In terms of establishing the norms for an outcome, there needs to be considerable attention devoted to the linkage between services and outcome. There are many extraneous factors that may influence outcomes associated with the service. There also is the need to consider the timing of an outcome. The outcomes for many services may be long delayed and may involve the receipt of additional services in the interim.

Some of these problems are very similar to issues raised in the discussion of risk adjustment. We need to develop measures that are going to be fair to the health plan, in that, as we hold them accountable for delivering services, we should be holding them accountable for services that do have a positive impact and for outcomes that are actually attainable.

While we are in the midst of this evolution of measures that can be used to assess the quality of care, we also need to consider whether we should allow the current state of our knowledge about quality measures to lead to actions that could preclude future improvement. In particular, one issue is whether plans should collect and provide purchasers encounter data describing all the services delivered. While there is increasing provision of HEDIS or FACCT measures to purchasers, there is some resistance to furnishing comprehensive encounter data .

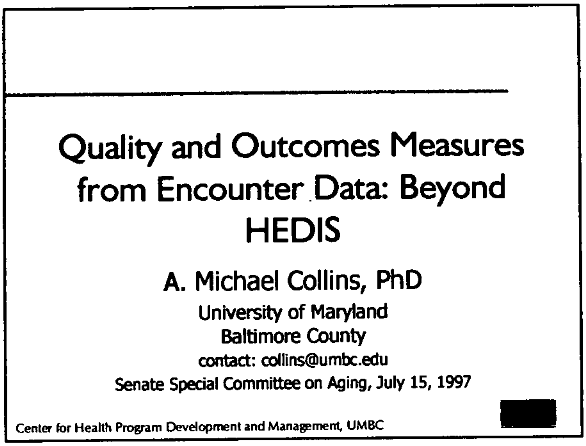
In part, the opposition to the provision of encounter data may be associated with the fact that, at this point, there are limited uses for such data because of the lack of appropriate conceptual measures for either the receipt of particular services or outcomes associated with services. While I believe that our set of valid and useful measures is going to improve over time, we need to be concerned about our ability to produce that information in the future. We need to be aware of the fact that if today we are developing information systems that are focused on the existing sets of HEDIS or FACCT measures, we are going to incur expensive retooling in the future in order to be able to provide the new measures for future HEDIS or future FACCT systems, or for some of their successors. By developing the capacity to collect encounter data today, there will be an opportunity to quickly implement different measures as they are developed.

It is also an often overlooked fact that encounter data will be essential for the rate setting process in the future. At this point, rate setting is an easy task -- let us say a relatively easy task, given all that has been said about the difficulties of risk adjustment-- because fee-for-service information about the receipt of services does exist and can be used as a benchmark for establishing rates. In the future, more and more individuals enrolling in managed care will result in much less fee-for-service data. The lack of encounter data then will be a significant barrier to establishing appropriate rates for the payment of services. One can only imagine how quickly this is going to happen, given the movement to managed care, as well as significant changes that the provision of medical services undergo as medical knowledge develops over time.

I think it is a positive step that many of the states have recognized the value and the need for encounter data. Seventeen states are collecting encounter data now and 5 more have indicated that they plan to collect encounter data in the near future. While these are positive steps, there remain some significant issues about the collection of encounter data, primarily associated with the appropriate processes to both validate and verify the information that is being provided. In the fee-for-service world, there is an axiom that data being used for payment purposes have significantly higher reliability than other information. Given that encounter data will generally not be used to determine payment, there is a risk that the data are not nearly as reliable as the fee-for-service information claims have been. Therefore, special steps need to be taken to ensure that the data are reasonably valid and reliable.

The last area that I would like to mention relates to the discussion last week about changing the definition of medical necessity as it applies to services for persons with special needs. A similar expansion is needed in talking about quality measures. There are dimensions other than access to services and the clinical outcomes associated with services that are very important to persons with special needs. We can think of these other dimensions, in some respects, as the amenities associated with the care that is being delivered. How convenient is it for individuals with special needs to get services, given what we know about their difficulty in terms of getting to physicians' offices or to other care centers, or their potential difficulties in moving around offices -- getting onto or sitting on examination tables? How hassle-free or pain-free plans make access are issues in addition to outcomes such as survival or level of functioning that may be very important to persons with special needs.

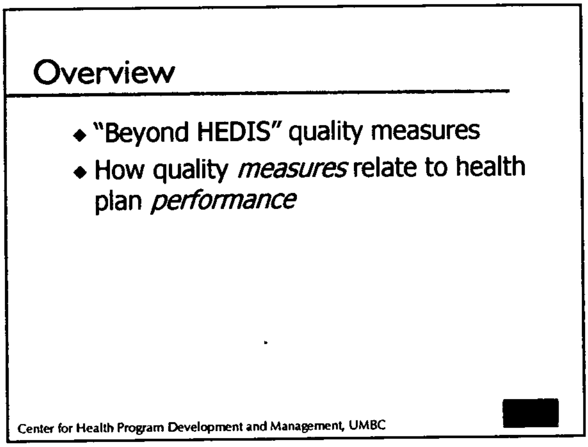
The last thing I would say about using accountability and oversight of managed care for persons with special needs is to reemphasize the very low prevalence of these special needs in the general population. Any monitoring system that is used has to stratify adequately in order to capture a sufficient number of individuals with special needs to ensure that how well plans serve their needs is being adequately monitored.



Quality and Outcomes Measures from Encounter Data: Beyond HEDIS

A. Michael Collins, PhD
University of Maryland
Baltimore County
contact: collins@umbc.edu
Senate Special Committee on Aging, July 15, 1997

Center for Health Program Development and Management, UMBC



Overview

- "Beyond HEDIS" quality measures
- How quality *measures* relate to health plan *performance*

Center for Health Program Development and Management, UMBC

HEDIS vs. quality measures

- HEDIS purpose: help purchasers compare plans, in general
- Quality measurement strategies:
  - Identify populations of special interest
  - Relate plan performance to treatment standards and guidelines
  - Improve information systems

Ambulatory Care Sensitive Conditions

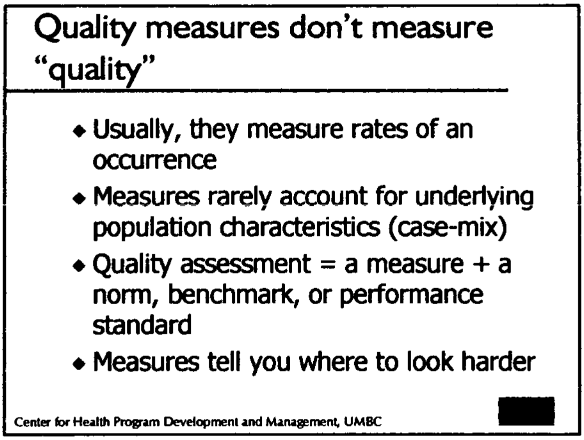
- Conditions for which timely and effective ambulatory care should lead to lower hospital admission rates
- Conditions should be tailored to the population served by the plan
- Maryland Medicaid has a list of 23 conditions

Maryland Medicaid Ambulatory Care Sensitive Condition examples

- Kids: immunizable conditions, congenital syphilis, dehydration, iron deficiency anemia, low birthweight, failure to thrive
- Adults or all: tuberculosis, epileptic convulsions, malignant hypertension, congestive heart failure, angina, severe ENT infections, pneumonia, ruptured appendix, PID, cellulitis, gangrene

Vulnerable population example: asthma in children

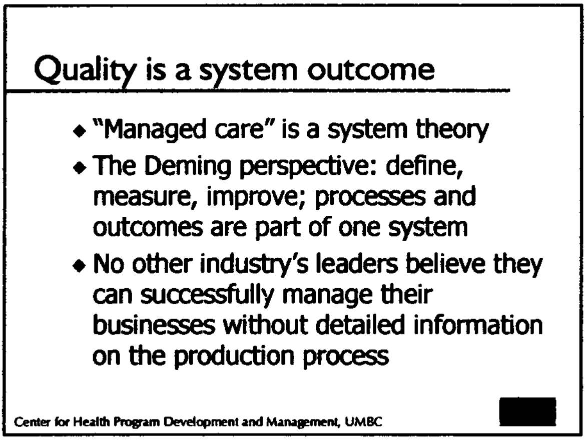
- HEDIS measure (version 2.5, not 3.0): hospital admission rate
- Number of ER visits
- Follow-up visit within six months of asthma diagnosis
- Follow-up visit within two months of oral steroid prescription



Quality measures don't measure "quality"

- Usually, they measure rates of an occurrence
- Measures rarely account for underlying population characteristics (case-mix)
- Quality assessment = a measure + a norm, benchmark, or performance standard
- Measures tell you where to look harder

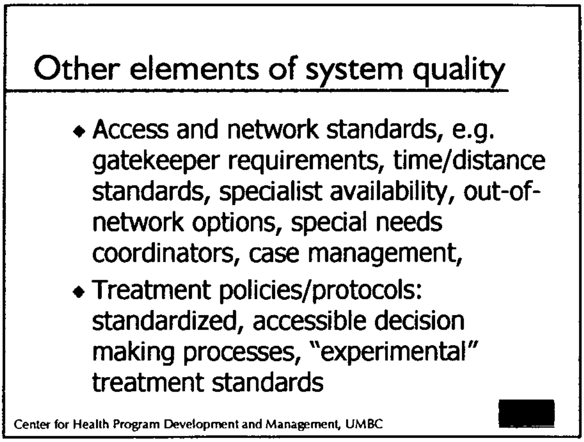
Center for Health Program Development and Management, UMBC



Quality is a system outcome

- "Managed care" is a system theory
- The Deming perspective: define, measure, improve; processes and outcomes are part of one system
- No other industry's leaders believe they can successfully manage their businesses without detailed information on the production process

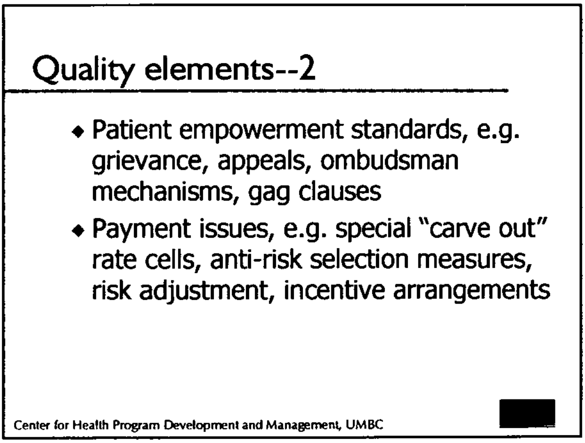
Center for Health Program Development and Management, UMBC



Other elements of system quality

- Access and network standards, e.g. gatekeeper requirements, time/distance standards, specialist availability, out-of-network options, special needs coordinators, case management,
- Treatment policies/protocols: standardized, accessible decision making processes, "experimental" treatment standards

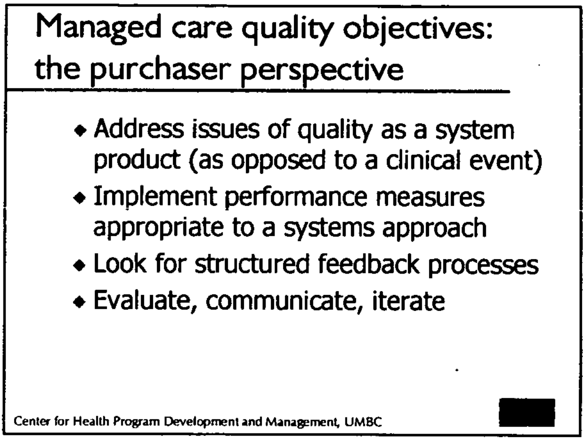
Center for Health Program Development and Management, UMBC



Quality elements--2

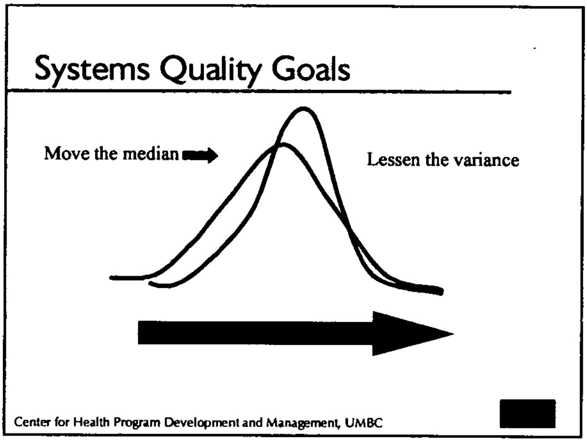
- Patient empowerment standards, e.g. grievance, appeals, ombudsman mechanisms, gag clauses
- Payment issues, e.g. special "carve out" rate cells, anti-risk selection measures, risk adjustment, incentive arrangements

Center for Health Program Development and Management, UMBC

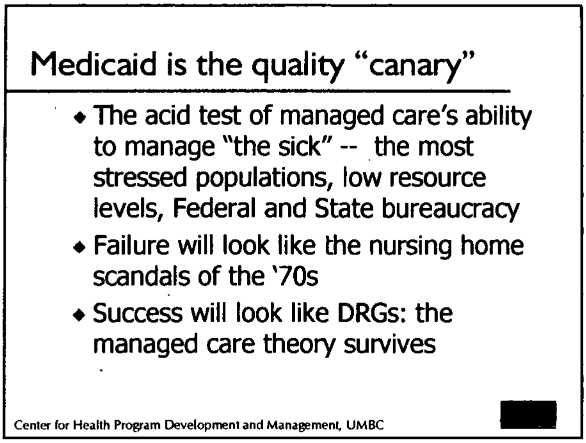


Managed care quality objectives: the purchaser perspective

- Address issues of quality as a system product (as opposed to a clinical event)
- Implement performance measures appropriate to a systems approach
- Look for structured feedback processes
- Evaluate, communicate, iterate

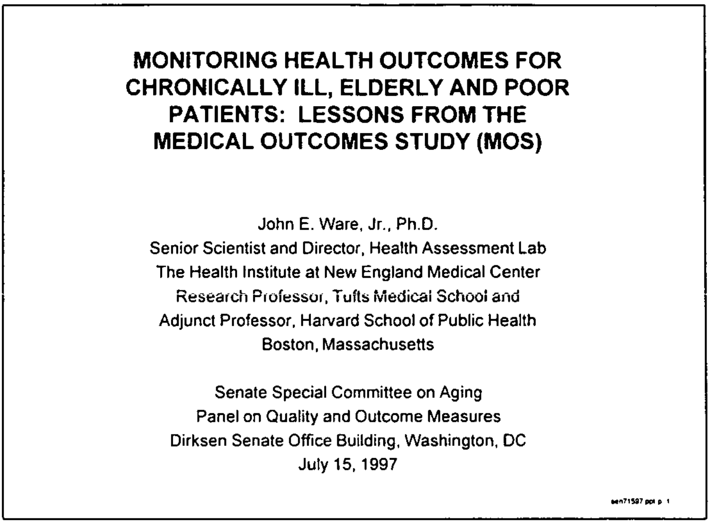


Systems Quality Goals



Medicaid is the quality “canary”

- The acid test of managed care’s ability to manage "the sick" -- the most stressed populations, low resource levels, Federal and State bureaucracy
- Failure will look like the nursing home scandals of the ‘70s
- Success will look like DRGs: the managed care theory survives

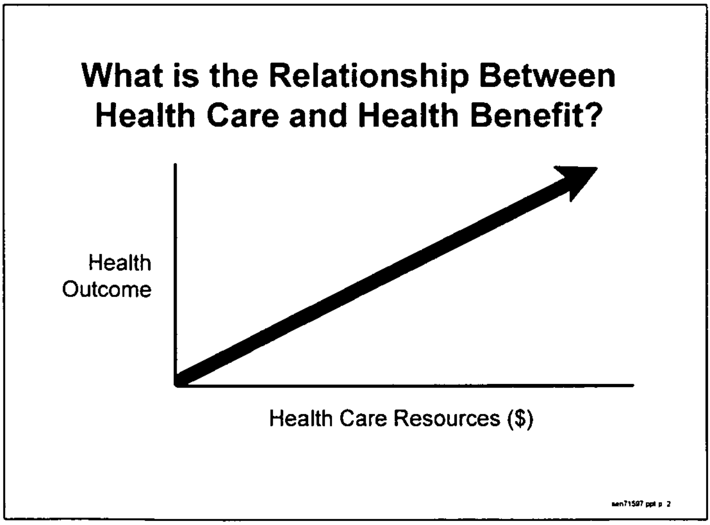


MONITORING HEALTH OUTCOMES FOR CHRONICALLY ILL, ELDERLY AND POOR PATIENTS: LESSONS FROM THE MEDICAL OUTCOMES STUDY (MOS)

John E. Ware, Jr., Ph.D.
Senior Scientist and Director, Health Assessment Lab
The Health Institute at New England Medical Center
Research Professor, Tufts Medical School and
Adjunct Professor, Harvard School of Public Health
Boston, Massachusetts

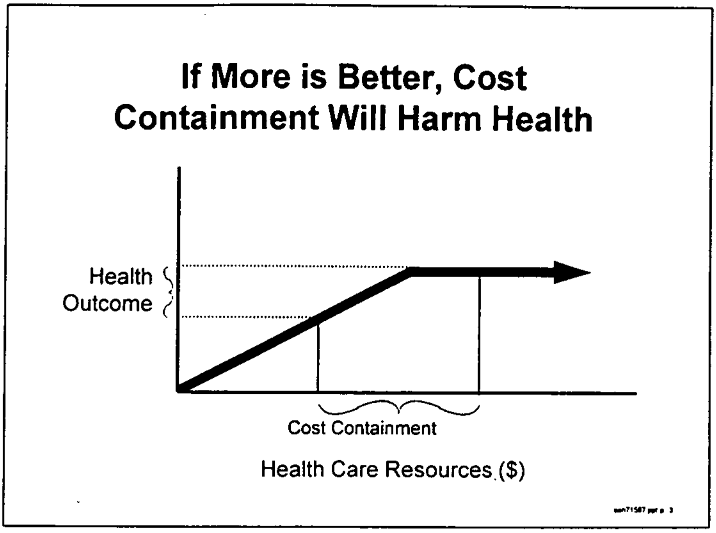
Senate Special Committee on Aging
Panel on Quality and Outcome Measures
Dirksen Senate Office Building, Washington, DC
July 15, 1997

sen71597.ppt p. 1



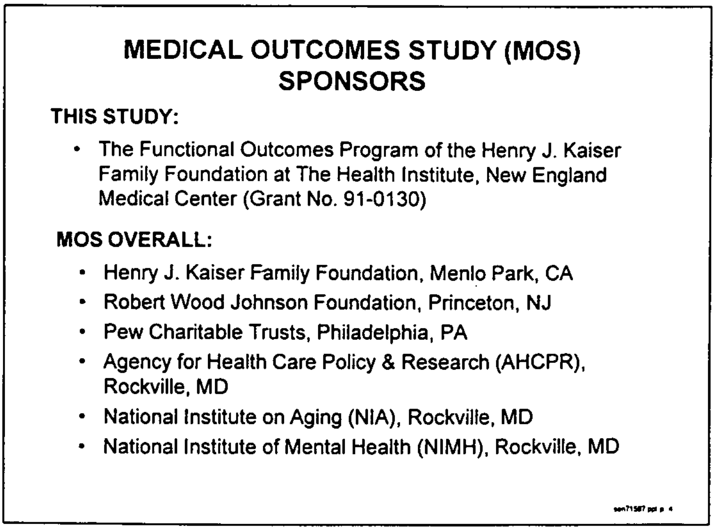
What is the Relationship Between Health Care and Health Benefit?

sen71597.ppt p. 2



If More is Better, Cost Containment Will Harm Health

sen71597.ppt p. 3



MEDICAL OUTCOMES STUDY (MOS) SPONSORS

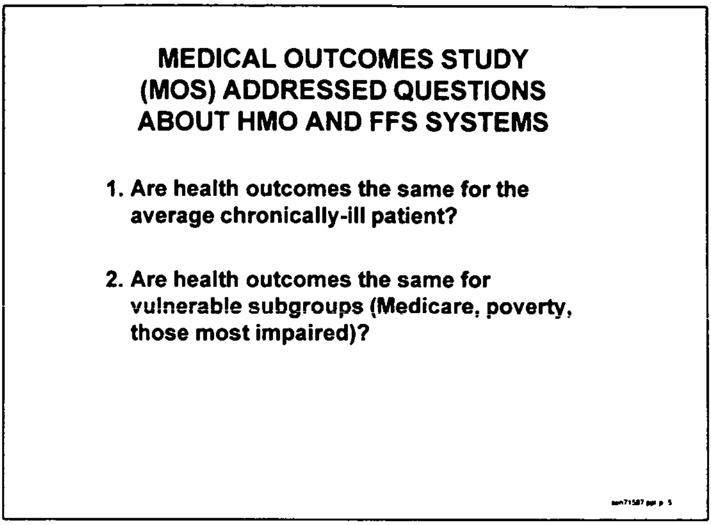
THIS STUDY:

- The Functional Outcomes Program of the Henry J. Kaiser Family Foundation at The Health Institute, New England Medical Center (Grant No. 91-0130)

MOS OVERALL:

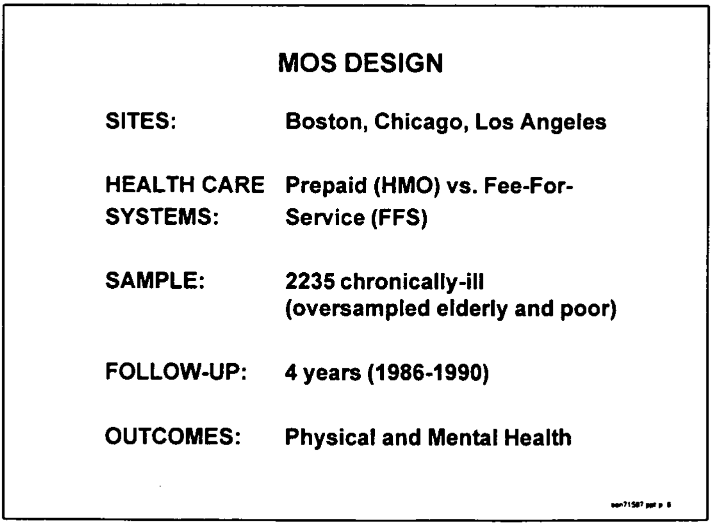
- Henry J. Kaiser Family Foundation, Menlo Park, CA
- Robert Wood Johnson Foundation, Princeton, NJ
- Pew Charitable Trusts, Philadelphia, PA
- Agency for Health Care Policy & Research (AHCPR), Rockville, MD
- National Institute on Aging (NIA), Rockville, MD
- National Institute of Mental Health (NIMH), Rockville, MD

sen71597.ppt p. 4



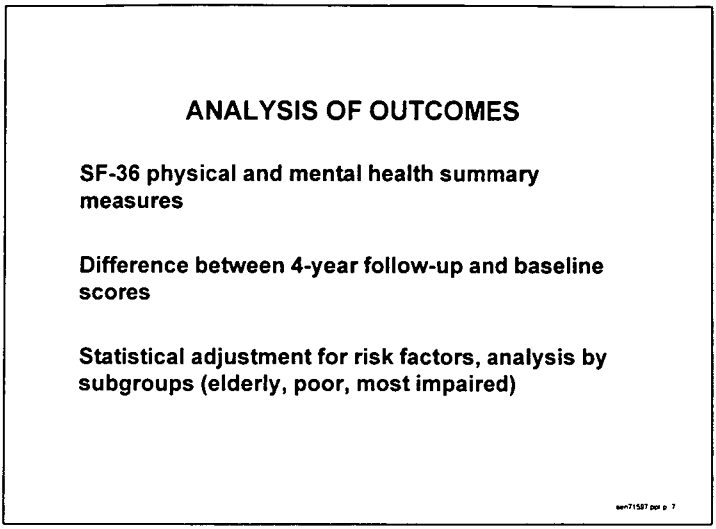
MEDICAL OUTCOMES STUDY (MOS) ADDRESSED QUESTIONS ABOUT HMO AND FFS SYSTEMS

1. Are health outcomes the same for the average chronically-ill patient?
2. Are health outcomes the same for vulnerable subgroups (Medicare, poverty, those most impaired)?



MOS DESIGN

SITES:	Boston, Chicago, Los Angeles
HEALTH CARE SYSTEMS:	Prepaid (HMO) vs. Fee-For-Service (FFS)
SAMPLE:	2235 chronically-ill (oversampled elderly and poor)
FOLLOW-UP:	4 years (1986-1990)
OUTCOMES:	Physical and Mental Health

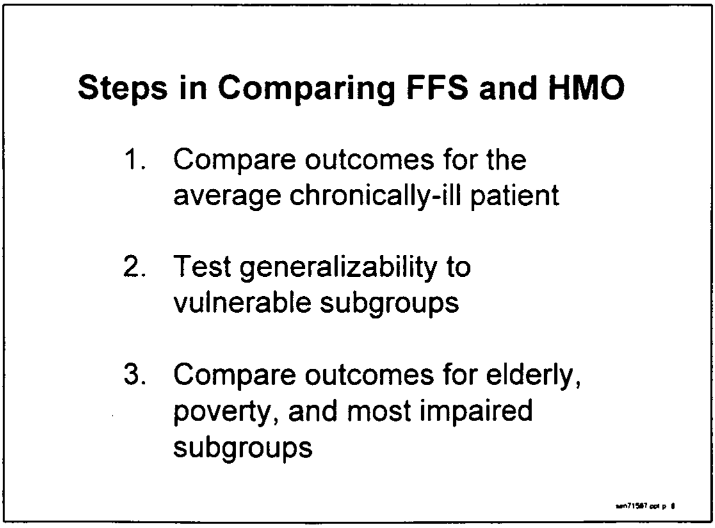


ANALYSIS OF OUTCOMES

SF-36 physical and mental health summary measures

Difference between 4-year follow-up and baseline scores

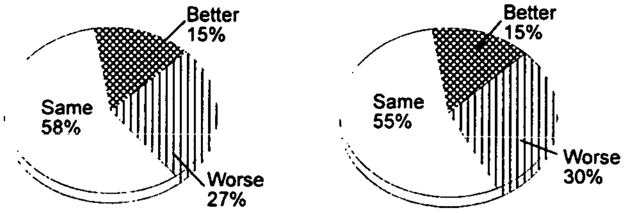
Statistical adjustment for risk factors, analysis by subgroups (elderly, poor, most impaired)



Steps in Comparing FFS and HMO

1. Compare outcomes for the average chronically-ill patient
2. Test generalizability to vulnerable subgroups
3. Compare outcomes for elderly, poverty, and most impaired subgroups

4-Year Physical Health Outcomes Were the Same in Analyses of All Chronically-Ill Patients



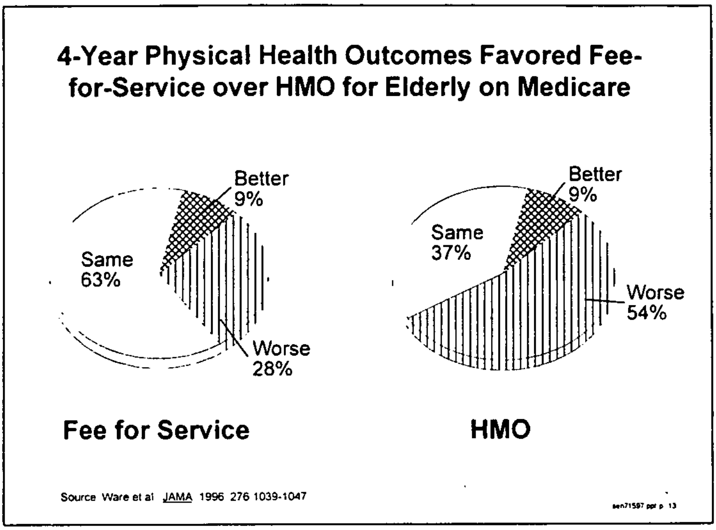
Fee for Service **HMO**

Source Ware et al., JAMA, 1996; 276 1039-1047

For the Average Patient, Physical Health Outcomes Were Equivalent Across Systems

System	Baseline Score	Four-Year Outcome			
		Δ	Worse (%)	Same (%)	Better (%)
FFS (N=1162)	45.2	-3.0	27	57	15
HMO (N=1073)	44.9	-3.1	30	55	15

Source: Medical Outcomes Study (MOS) (Ware, Bayliss, Rogers et al 1996, JAMA, 276, 13, 1039-1047, see Table 3

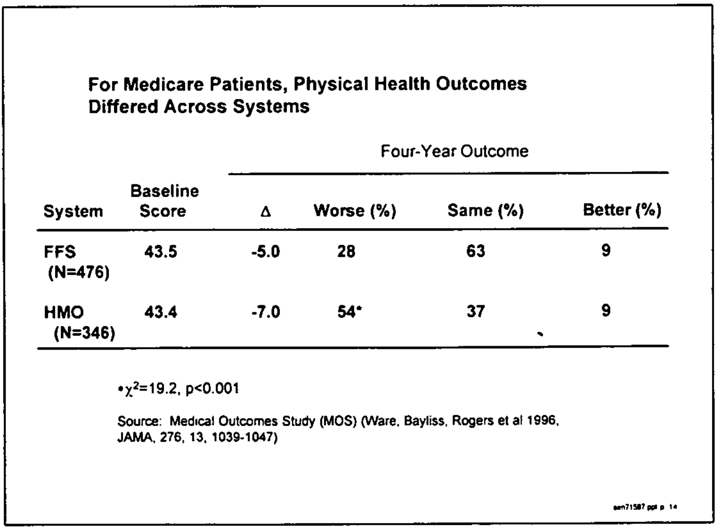


4-Year Physical Health Outcomes Favored Fee-for-Service over HMO for Elderly on Medicare

Fee for Service **HMO**

Source Ware et al JAMA 1996 276 1039-1047

sen71597.ppt p. 13



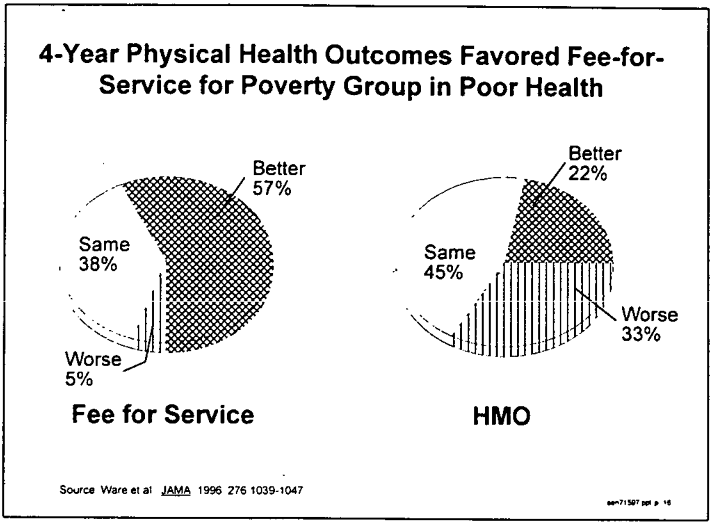
For Medicare Patients, Physical Health Outcomes Differed Across Systems

System	Baseline Score	Four-Year Outcome Δ	Worse (%)	Same (%)	Better (%)
FFS (N=476)	43.5	-5.0	28	63	9
HMO (N=346)	43.4	-7.0	54*	37	9

•χ^2=19.2, p<0.001

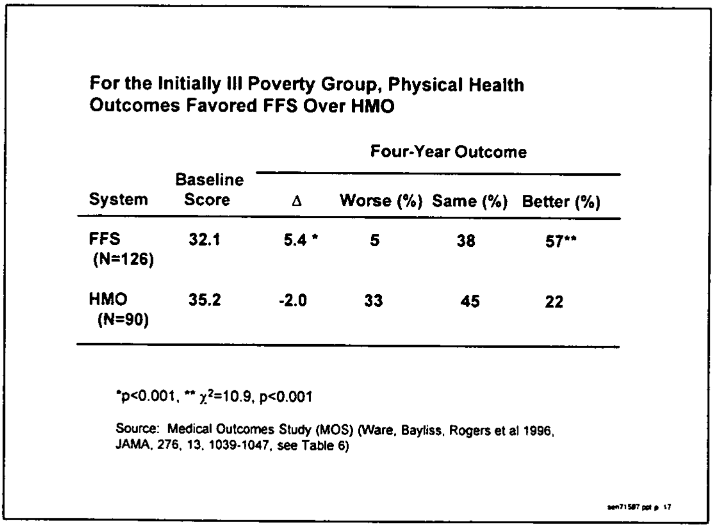
Source: Medical Outcomes Study (MOS) (Ware, Bayliss, Rogers et al 1996, JAMA, 276, 13, 1039-1047)

sen71597.ppt p. 14



4-Year Physical Health Outcomes Favored Fee-for-Service for Poverty Group in Poor Health

Source Ware et al JAMA 1996 276 1039-1047

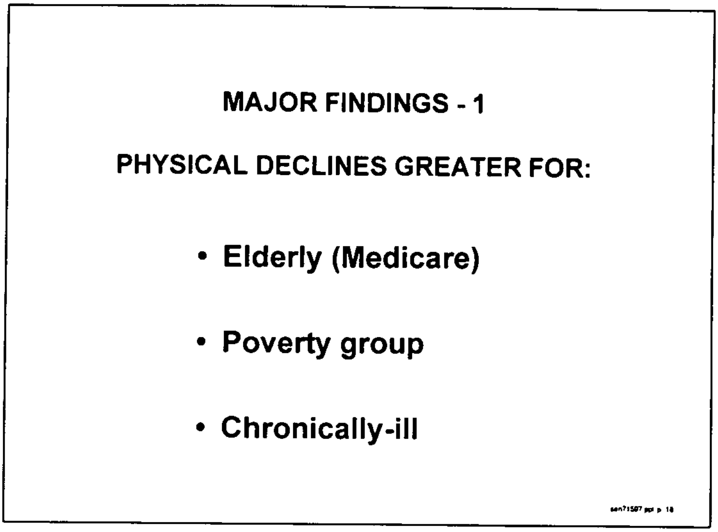


For the Initially Ill Poverty Group, Physical Health Outcomes Favored FFS Over HMO

System	Baseline Score	Four-Year Outcome			
		Δ	Worse (%)	Same (%)	Better (%)
FFS (N=126)	32.1	5.4 *	5	38	57**
HMO (N=90)	35.2	-2.0	33	45	22

*$p<0.001$, ** $\chi^2=10.9$, $p<0.001$

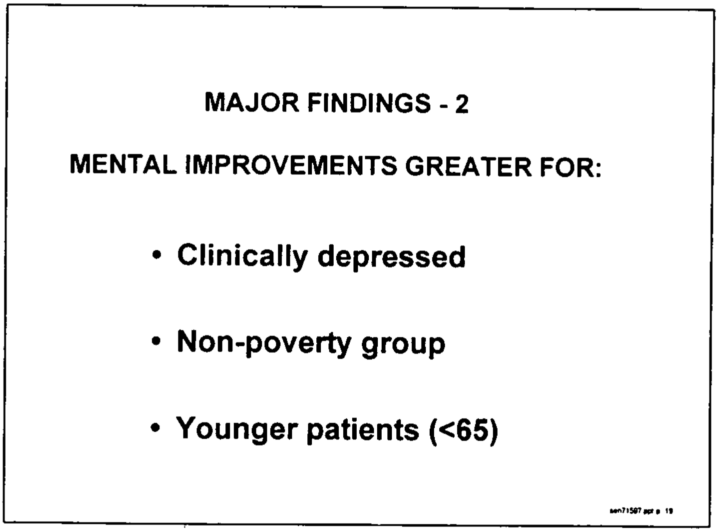
Source: Medical Outcomes Study (MOS) (Ware, Bayliss, Rogers et al 1996, JAMA, 276, 13, 1039-1047, see Table 6)



MAJOR FINDINGS - 1

PHYSICAL DECLINES GREATER FOR:

- Elderly (Medicare)
- Poverty group
- Chronically-ill



MAJOR FINDINGS - 2

MENTAL IMPROVEMENTS GREATER FOR:

- Clinically depressed
- Non-poverty group
- Younger patients (<65)

MAJOR FINDINGS - 3

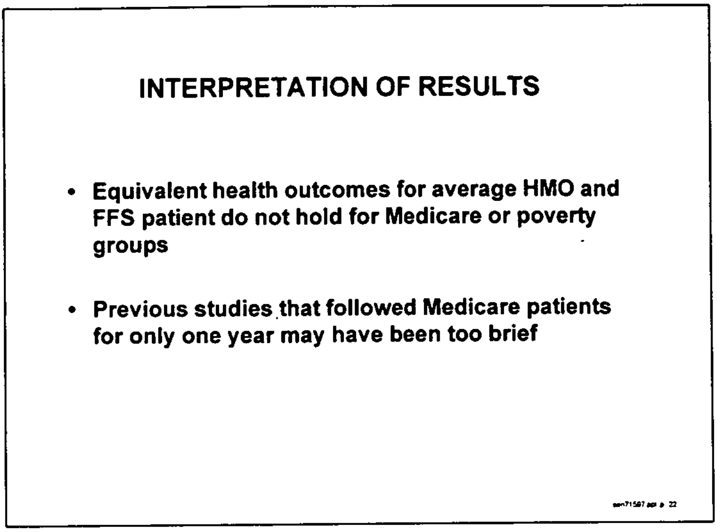
ON AVERAGE, OUTCOMES DID NOT DIFFER BETWEEN HMO AND FFS SYSTEMS

RESULTS OF SYSTEM COMPARISONS DIFFERED:

- Elderly (Medicare): FFS > HMO
- Poverty group: FFS > HMO
- Most impaired: FFS > HMO
- Across study sites for mental health

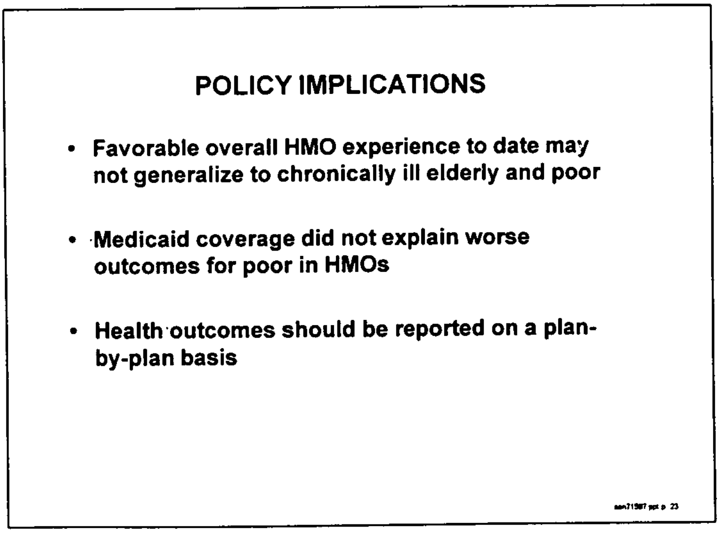
LIMITATIONS OF THE MOS

- Data collected in 1986-1990
- Not a randomized trial
- Only three large cities
- Small samples for some comparisons
- Information about treatment and clinical correlates of outcomes limited
- Short follow-up period relative to the duration of chronic disease
- Some patients switched plans (20%) or were lost to follow-up (30%)



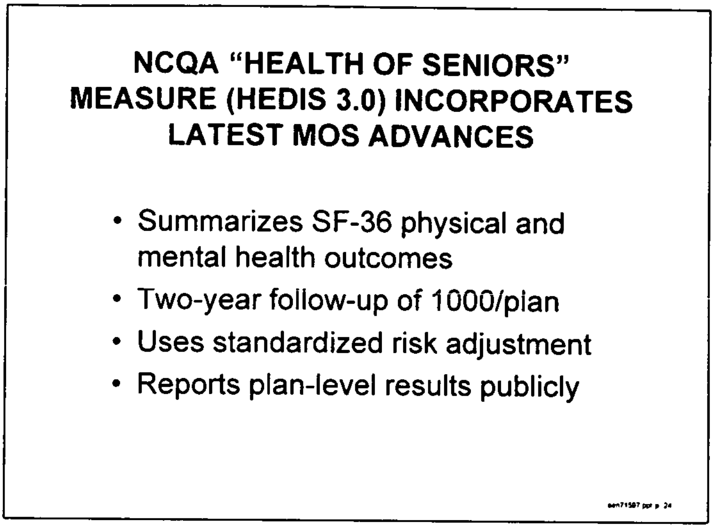
INTERPRETATION OF RESULTS

- Equivalent health outcomes for average HMO and FFS patient do not hold for Medicare or poverty groups
- Previous studies that followed Medicare patients for only one year may have been too brief



POLICY IMPLICATIONS

- Favorable overall HMO experience to date may not generalize to chronically ill elderly and poor
- Medicaid coverage did not explain worse outcomes for poor in HMOs
- Health outcomes should be reported on a plan-by-plan basis



NCQA "HEALTH OF SENIORS" MEASURE (HEDIS 3.0) INCORPORATES LATEST MOS ADVANCES

- Summarizes SF-36 physical and mental health outcomes
- Two-year follow-up of 1000/plan
- Uses standardized risk adjustment
- Reports plan-level results publicly

Additional Information is on the Internet at:

www.sf-36.com

Selected MOS References:

Greenfield S, Nelson EC, Zubkoff M *et al.* Variations in resource utilization among medical specialties and systems of care: results from the Medical Outcomes Study. *Journal of the American Medical Association* 1992; 267(12):1624-30.

Kravitz RL, Greenfield S, Rogers WH *et al.* Differences in the mix of patients among medical specialties and systems of care: results from the Medical Outcomes Study. *Journal of the American Medical Association* 1992; 267(12):1617-23.

Rogers WH, Wells KB, Meredith LS, Sturm R, Burnam A. Outcomes for adult outpatients with depression under prepaid or fee-for-service financing. *Archives of General Psychiatry* 1993; 50(7):517-25.

Rubin H, Gandek B, Rogers WH, Kosinski M, McHorney CA, Ware JE. Patients' ratings of outpatient visits in different practice settings: results from the Medical Outcomes Study. *Journal of the American Medical Association* 1993; 270(7):835-40.

Safran DG, Tarlov AR, Rogers W. Primary care performances in fee-for-service and prepaid health care systems: results from the Medical Outcomes Study. *Journal of the American Medical Association* 1994; 271(20):1579-86.

Stewart AL, Greenfield S, Hays RD *et al.* Functional status and well-being of patients with chronic conditions: results from the Medical Outcomes Study. *Journal of the American Medical Association* 1989; 262(7):907-13.

Tarlov AR, Ware JE, Greenfield S, Nelson EC, Perrin E, Zubkoff M. The Medical Outcomes Study: an application of methods for monitoring the results of medical care. *Journal of the American Medical Association* 1989; 262(7):925-30.

Ware JE, Bayliss MS, Rogers WH, Kosinski M, Tarlov AR. Differences in four-year health outcomes for elderly and poor, chronically ill patients treated in HMO and fee-for-service: results from the Medical Outcomes Study. *Journal of the American Medical Association* 1996; 276(13):1039-47.

Ware JE, Kosinski M, Bayliss MS, McHorney CA, Rogers WH, Raczek A. Comparison of methods for scoring and statistical analysis of SF-36 health profiles and summary measures: summary of results from the Medical Outcomes Study. *Medical Care* 1995; 33(Suppl. 4):AS264-79.

Wells KB, Hays RD, Burnam MA, Rogers W, Greenfield S, Ware JE. Detection of depressive disorder for patients receiving prepaid or fee-for-service care: results from the Medical Outcomes Study. *Journal of the American Medical Association* 1989; 262(23):3298-302.

Differences in 4-Year Health Outcomes for Elderly and Poor, Chronically Ill Patients Treated in HMO and Fee-for-Service Systems

Results From the Medical Outcomes Study

John E. Ware, Jr, PhD; Martha S. Bayliss, MSc; William H. Rogers, PhD; Mark Kosinski, MA; Alvin R. Tarlov, MD

Objective.—To compare physical and mental health outcomes of chronically ill adults, including elderly and poor subgroups, treated in health maintenance organization (HMO) and fee-for-service (FFS) systems.

Study Design.—A 4-year observational study of 2235 patients (18 to 97 years of age) with hypertension, non–insulin-dependent diabetes mellitus (NIDDM), recent acute myocardial infarction, congestive heart failure, and depressive disorder sampled from HMO and FFS systems in 1986 and followed up through 1990. Those aged 65 years and older covered under Medicare and low-income patients (200% of poverty) were analyzed separately.

Setting and Participants.—Offices of physicians practicing family medicine, internal medicine, endocrinology, cardiology, and psychiatry, in HMO and FFS systems of care. Types of practices included both prepaid group (72% of patients) and independent practice association (28%) types of HMOs, large multispecialty groups, and solo or small, single-specialty practices in Boston, Mass, Chicago, Ill, and Los Angeles, Calif.

Outcome Measures.—Differences between initial and 4-year follow-up scores of summary physical and mental health scales from the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) for all patients and practice settings.

Results.—On average, physical health declined and mental health remained stable during the 4-year follow-up period, with physical declines larger for the elderly than for the nonelderly ($P<.001$). In comparisons between HMO and FFS systems, physical and mental health outcomes did not differ for the average patient; however, they did differ for subgroups of the population differing in age and poverty status. For elderly patients (those aged 65 years and older) treated under Medicare, declines in physical health were more common in HMOs than in FFS plans (54% vs 28%; $P<.001$). In 1 site, mental health outcomes were better ($P<.05$) for elderly patients in HMOs relative to FFS but not in 2 other sites. For patients differing in poverty status, opposite patterns of physical health ($P<.05$) and for mental health ($P<.001$) outcomes were observed across systems; outcomes favored FFS over HMOs for the poverty group and favored HMOs over FFS for the nonpoverty group.

Conclusions.—During the study period, elderly and poor chronically ill patients had worse physical health outcomes in HMOs than in FFS systems; mental health outcomes varied by study site and patient characteristics. Current health care plans should carefully monitor the health outcomes of these vulnerable subgroups.

JAMA. 1996;276:1039-1047

ENROLLMENTS in health maintenance organizations (HMOs) have increased nearly 10-fold since 1976, and in some regions of the country, half of privately insured Americans are enrolled in HMOs.[1] Policies at the state and federal levels seek to affect a similar shift for those who are publicly insured, including both Medicare and Medicaid. Congress has signed legislation that will give Medicare patients strong financial incentives to enroll in managed care plans. Yet, as documented in a recent literature analysis,[2] little is known about health outcomes in HMOs for the elderly and the poor, who have historically tended to favor fee-for-service (FFS) over HMO systems.

The Medical Outcomes Study (MOS) was fielded to compare 4-year health outcomes for chronically ill patients treated in well-established HMOs and FFS plans serving the same "medical marketplaces" in 3 cities.[3] To increase the generalizability of results, adults with 4 physical conditions (hypertension, non–insulin-dependent diabetes mellitus [NIDDM], recent acute myocardial infarction, and congestive heart failure) and 1 mental condition (depressive dis-

---

From The Health Institute, New England Medical Center (Drs Ware, Rogers, and Tarlov, Ms Bayliss, and Mr Kosinski), Tufts University School of Medicine (Drs Ware and Tarlov), and Harvard School of Public Health (Drs Ware and Tarlov), Boston, Mass.

Reprints: John E. Ware, Jr, PhD, The Health Institute, New England Medical Center, Box 345, 750 Washington St, Boston, MA 02111 (e-mail: john.ware@es.nemc.org).

order) were followed. Sampling patients with the same diagnoses across systems of care and measuring them with the same methods allowed more valid comparisons of outcomes across plans. To better address policy issues, the MOS oversampled the elderly and the poor. Focusing on chronically ill patients and oversampling of the elderly and poor increased the likelihood of detecting differences in health outcomes because these subgroups account for a disproportionate share of health care expenditures and are, therefore, prime targets of cost containment.

We report here the results of comparing changes in physical and mental health status between FFS and HMO systems, measured over a 4-year period. In contrast to previous MOS reports of outcomes for the average patient, we focus on outcomes for policy-relevant subgroups—including patients aged 65 years and older covered by Medicare and those near and below the poverty line. Further, results are reported for patients across all of the conditions sampled in the MOS and not just for patients with hypertension and NIDDM[4] and mental disorders.[5,6]

METHODS

The MOS was an observational study of variations in practice styles and of outcomes for chronically ill adults treated in staff-model and independent practice HMOs vs FFS care in large multispecialty groups, small, single-specialty groups, and solo practices serving the same areas. Details of the MOS design, including site selection, sampling, clinician and patient recruitment, and data collection methods are documented elsewhere.[3-12] To briefly recap the study design, MOS sites included Boston, Mass, Chicago, Ill, and Los Angeles, Calif, which represent 3 of the 4 US census regions. When sampling began in 1986 and 1987, these cities included well-developed HMO and FFS plans, including 2 of the country's largest HMOs employing salaried physicians and 2 of the largest independent practice association (IPA) networks. In each city, 5 or 6 practice sites were sampled from each group practice HMO. The physician sample included 206 general internists, 87 family practitioners, 42 cardiologists, 27 endocrinologists, and 65 psychiatrists. In HMOs, patients treated by 8 nurse practitioners were also sampled. In addition, patients with a depressive disorder were sampled from the practices of 59 clinical psychologists and 9 social workers. Clinicians averaged 39.6 years of age; 22% were female, and 29% were international medical graduates.

Patient Sampling and Characteristics

Patients followed up longitudinally were selected from 28 257 adults who visited an MOS site in 1986; 71.6% agreed to participate. In 18 794 (92.9%) of the visits, a standardized screening form was completed both by the MOS clinician and the patient. Using criteria documented elsewhere,[3] clinicians identified patients with hypertension, NIDDM, myocardial infarction within the past 6 months, and congestive heart failure. Patients with depressive disorder were identified independently in a 2-stage screen, which included a patient-completed form and a computer-assisted diagnostic interview by telephone[3]; 80% of those contacted completed this screening process.

Patients were selected for follow-up on the basis of diagnosis and participation in baseline data collection, as documented in detail elsewhere.[6,7] Inclusion of patients with more than 1 of the 5 conditions, with or without other comorbidities, allowed for a more generalizable study. Of the 3589 eligible patients, 2708 (75.5%) completed a baseline assessment. We randomly selected 2235 of these for follow-up, by chronic condition and severity of their disease. A patient sample of this size was sufficient to detect clinically and socially relevant differences in health outcomes, defined as an average difference of 2 points or larger on a scale of 0 to 100,[3] in a comparison between HMO and FFS systems. Specifically, the statistical power was greater than 80%, with α at the .05 level for a 2-tailed test.

Patients ranged from 18 to 97 years of age, with a mean just under 58 years. At baseline, 36.8% were 65 years of age or older; all but 1 reported being covered by Medicare. (An additional 144 patients aged into this group during the 4-year follow-up.) A slight majority (54%) were female. About 22% were at or below 200% of the poverty line; 16% of those reported being covered by Medicaid. Three of 10 eligible for Medicare were also in the poverty group. Three of 4 had completed at least a 12th grade education; about 1 in 5 was nonwhite.

Patients sampled had the following diagnoses: hypertension (n=1318), NIDDM (n=441), congestive heart failure (n=215), recent acute myocardial infarction (n=104), and depressive disorder (n=444). (These numbers add to more than 2235 because some patients had more than one condition.)[7,9] As in previous MOS analyses,[8] FFS patients followed up in this study were significantly older (41.9 vs 32.9 years on average) than HMO patients, were more likely to be female (62.8% vs 57.8%), and were more likely to be in the poverty group (25.4% vs 18.1%). The FFS patients followed were also more likely to have congestive heart failure (11.8% vs 7.3%) and to have had a recent myocardial infarction (8.9% vs 3.4%). As documented in detail elsewhere (MOS unpublished data; see acknowledgment footnote at the end of this article for availability of all MOS unpublished data), 99% of patients followed in both FFS and HMO systems had 1 or more comorbid conditions; the most prevalent conditions were back pain/sciatica (39% and 37% in FFS and HMO systems, respectively), musculoskeletal complaints (24% and 22%), dermatitis (17% in each), and varicosities (15% and 14%).

Longitudinal Data Collection

After screening in the physician's office and enrollment by telephone interview, each patient was sent a baseline health survey by mail.[10] The baseline survey was completed, on average, 4 months after the patient's screening visit with an MOS clinician. Four-year follow-up data were obtained for 1574 of the 2235 patients (70.4% of the longitudinal cohort). Patients were lost to follow-up for a variety of reasons including refusals and failure to contact (n=661; 29.6%); 137 (6.1%) who died during follow-up were included in the analysis. Analysis of initial health status for those lost to follow-up for reasons other than death revealed no differences and loss to follow-up was equally likely in HMO and FFS systems. However, younger and poverty-stricken patients were more likely to be lost from both HMO and FFS systems. All analyses of outcomes adjusted for age, poverty status, and other variables to take into account this potential source of bias (see "Statistical Analysis").

Health Status Measures

Summary physical and mental health scales constructed from the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) were analyzed (Table 1). These summary measures capture 82% of the reliable variance in the 8 SF-36 health scores estimated using the internal-consistency reliability method.[13-15] The construction of summary measures, score reliability and validity, and normative and other interpretation guidelines are documented elsewhere.[13,14]

Changes in health were estimated in 2 ways. First, baseline scores were subtracted from 4-year follow-up✓scores, with deaths assigned a follow-up physical health score of 0 (Table 1). Although these average change scores have the advantage of reflecting the magnitude of change in the metric of the scales, they mask the proportion of patients with follow-up scores that differed from those at baseline. Therefore, individual patients also were classified into 3 change categories: (1) those whose follow-up score did not change more than would be expected by chance ("same" group); (2) those who improved more than would be expected ("better" group); and (3) those whose score declined more than would be expected and those who died ("worse" group) (Table 1). This latter method has the advantage of combining health status and mortality without making any assumption about the "scale value" of death. Unlikely to be due to measurement error, changes large enough to be labeled better or worse also have been shown to be relevant in terms of a wide range of clinical and social criteria.[13]

Estimates of health outcomes for survivors only were substantially biased because deaths were more common among those with congestive heart failure, aged 65 years and older, and under FFS care; deaths were less likely for the clinically depressed group. Differences in survival rates between FFS and HMO systems were insignificant after adjustment for baseline patient characteristics. Thus, alternative methods of coding deaths[16] in estimating outcomes did not affect comparisons between FFS and HMO systems (MOS unpublished data).

Statistical Analysis

The goal of the analysis was to compare HMO and FFS systems of care in terms of average changes in health status and in terms of the percentages of patients who were better, the same, or worse at follow-up. These outcomes were estimated for all patients, and separately for subgroups differing in age, poverty status, and initial health. Multivariate statistical methods were used to adjust baseline scores so that the HMO and FFS groups would begin as equal as possible in terms of demographic and socioeconomic characteristics, study site, chronic conditions, disease severity, comorbid conditions, initial health status, and other design variables (Table 2).

Independent regression models were estimated for physical and mental health summary measures, and F tests of significance determined whether adjusted change scores differed, on average, across HMO and FFS systems. To make sure that the summary measures did not miss a difference concentrated in 1 of the 8 scales, all comparisons between FFS and HMO systems also were replicated for each of the 8 SF-36 scales. Because the summary measures captured all significant differences, results of their analyses are reported here. Results for the 8 SF-36 scales are documented elsewhere (MOS unpublished data).

Multinominal (polytomous) logistic regression[17] methods were used to compare categorical changes (better, same, worse) in physical and mental health across HMO and FFS systems for the total sample and for the subgroups. Adjusted percentages for change categories were generated with statistical adjustments for the same baseline characteristics used in linear models (Table 2). The χ^2 tests of significance were computed to determine whether the percentages across change categories differed between HMO and FFS systems of care.

Comparisons of outcomes across systems reported here combine results for IPA "network" and staff-model HMOs. As in previous MOS analyses,[4] there were no significant differences in outcomes for those in IPAs and staff-model HMOs in any of the analyses performed and there were no consistent trends suggesting a difference between IPAs and staff-model HMOs. However, because only 28% of prepaid patients were sampled from IPAs, the MOS did not have enough statistical power to meaningfully compare outcomes across types of HMOs.

To facilitate interpretation, regression models were used to estimate adjusted outcomes for the total sample and for each subgroup in comparing outcomes between FFS and HMO systems. Formal statistical tests for interactions were performed to determine whether conclusions about differences between systems were the same across subgroups differing in age (Medicare), poverty status, Medicaid coverage, and initial health. To test for differences in outcomes for groups in better or worse initial health status, patients were stratified using baseline physical and mental health measures, both for linear and logistic regression models. Thirds of the sample were identified based on whether they were functioning (physically or mentally) higher, lower, or as would be expected at baseline, given their age and medical condition (Table 2).

In keeping with the logic of an intention-to-treat analysis, patients were analyzed according to the system from which they were sampled. In support of this decision, the great majority of patients had been in their system 4 years or more at the time of sampling and most who switched did not do so for another 2 years. Thus, more than two thirds of those who switched systems during the 4-year follow-up had been in the type of system they were sampled from for 6 or more years before switching. However, because MOS pa-

Table 1.—Definitions of Baseline and Outcome Health Measures

Baseline	
Physical health	36-Item Short-Form Health Survey (SF-36) Physical Health Summary Scale, standardized to have a mean=50, SD=10 in the general US population.[13] Internal-consistency reliability=0.91; test-retest reliability=0.89, which exceed the minimum standard suggested for group-level comparisons.[13]
Mental health	SF-36 Mental Health Summary Scale, standardized to have mean=50, SD=10 in the general US population.[13] Internal-consistency reliability=0.87; test-retest reliability=0.80, which exceed the minimum standard suggested for group-level comparisons.[13]
Mean changes	
Physical health	Calculated for all patients as [(score at 4-year follow-up)−(baseline score)], prorated to adjust for unequal time intervals. Patients who died during the study were assigned a score of 0 at 4-year follow-up.[16] A score of 0 falls about 1 SD below the worst possible score, a score that was observed among MOS survivors. A score of 0 is also about 1 SD below the worst health state quantified in preliminary studies of an SF-36–based utility index, which combines health status and mortality. Sensitivity analyses with deaths scored 1 SD above and 1 SD below a score of 0 did not change conclusions about differences in health outcomes between fee-for-service and prepaid health maintenance (HMO) plans (MOS unpublished data).
Mental health	Calculated for surviving patients as [(score at 4-year follow-up)−(baseline score)], prorated to adjust for unequal time intervals.
Categories of change	
Physical health	Each patient was classified into 1 of 3 categories, according to the direction and magnitude of change between baseline and 4-year follow-up. Patients whose scores declined by more than 6.5 points were categorized as worse. Those who scores improved by more than 6.5 points were categorized as better. Those whose scores were within 6.5 points at baseline and follow-up were classified as same. Patients who died during the follow-up period were included in the worse group. As documented elsewhere,[13] a change greater than 6.5 is outside of the 95% confidence interval for an individual patient score, as estimated from the SD and score reliability.[13] Differences this large have been shown to be clinically and socially relevant. For example, average improvements in SF-36 Physical Health Summary scores this large or larger were observed following heart valve replacement surgery and total hip arthroplasty; such improvements are predictive of a one third decrease in probability of job loss, within the next year, among working patients.[13] Patients who declined enough to be classified as worse in physical health at the end of 4 years were nearly 10 times more likely (0.9% vs 8.1%, $P<.001$) to die during the subsequent 3 years.
Mental health	Each surviving patient was classified into 1 of 3 categories according to the direction and magnitude of change between baseline and 4-year follow-up. Patients whose scores declined by more than 7.9 points were categorized as worse, those whose scores improved by more than 7.9 points were categorized as better, and those whose scores were within 7.9 points were classified as same. A change of this amount is outside the 95% confidence interval for an individual patient score.[13] An improvement in mental health nearly this large was observed for the average elderly depressed patient who responded to drug treatment in comparison with nonresponders.[25]

Table 2.—Covariates Used in the Estimation of Regression Adjusted Health Change Scores

- Main effects
  - System of care
    - Sampled from prepaid health maintenance organization (HMO) or fee-for-service care*
  - Age
    - Age ≥65 y or age <65 y, classified at baseline
  - Sex
    - Male or female
  - Race
    - White, black, or other minority
  - Poverty status
    - Above or below 200% of poverty, defined as per capita household income in 1986 dollars
  - Medical Outcomes Study (MOS) tracer conditions
    - Hypertension, myocardial infarction (MI), congestive heart failure, non–insulin-dependent diabetes mellitus, depressive disorder
  - Comorbid medical conditions†
    - Asthma, chronic obstructive pulmonary disease, angina (ever), angina (recent, no MI), MI past, other lung disease, back pain/sciatica, hip impairments, rheumatoid arthritis, osteoarthritis, musculoskeletal complaints, other rheumatic disease, colitis, diverticulitis, fistulas, gallbladder disease, irritable bowel disease, liver disease, type I diabetes mellitus, ulcer, kidney disease, benign prostatic hypertrophy, urinary tract infection, varicosities, cancer, dermatitis, anemia
  - Initial physical or mental health
    - Tertiles of baseline health status estimated from multiple linear regression models that adjusted for age, MOS tracer conditions, and comorbid medical conditions. Initial tertiles labeled as "good," "average," and "ill" health were defined by thirds of the distribution of residuals from each regression model; these patients were, respectively, functioning better than expected, as expected, or worse than expected, given their age and medical condition
  - MOS design variables
    - Study site, cluster sampling of patients within physician offices, seasonality, weights for unequal probability caused by design choices and nonresponse
- Two-way interaction terms
  - HMO and age ≥65 y
  - HMO and poverty status
  - HMO and physical or mental health tertiles
  - Age ≥65 y and poverty
  - Age ≥65 y and physical or mental health tertiles
  - Poverty and physical or mental health tertiles
- Three-way interaction terms
  - HMO and age ≥65 and physical or mental health tertiles
  - HMO and poverty and physical or mental health tertiles

*Thirty patients (1.9% of those followed) who reported no insurance coverage were included in the fee-for-service group. All were younger than 65 years. Analyses excluding the uninsured group did not change the conclusions from comparisons between systems reported here.

†Information regarding the comorbid medical conditions was obtained from the patient during a structured medical history interview conducted by a trained clinician. If information regarding a condition (or conditions) was missing, an independently derived probability of each diagnosis was substituted. Because of very low prevalence, the following conditions are incorporated into an index of 11 comorbid conditions: angina (ever), other rheumatic disease, colitis, diverticulitis, intestinal fistulas, gallbladder disease, liver disease, benign prostatic hypertrophy, varicosities, cancer, and type I diabetes mellitus.

tients were more likely to switch from an HMO than from an FFS plan (20% vs 15%; $P<.01$), estimates of outcomes could have been biased. This potential source of bias was evaluated by comparing rates of switching within elderly and poverty subgroups along with average outcomes for those who did and did not switch. As documented elsewhere (MOS unpublished data), the relative probability of switching from an HMO observed within the elderly and poverty subgroups was comparable to that for the total sample. Further, baseline scores and average changes in physical and mental health did not differ significantly for those who did and did not switch plans within either subgroup (MOS unpublished data). Thus, conclusions about system differences in health outcomes are not likely to have been biased by the intention-to-treat method of analysis used in this study.

To evaluate whether differences in rates of loss to follow-up were a source of bias in comparisons of outcomes between systems, these rates were compared for the total sample and separately for the elderly and poverty subgroups. As documented in detail elsewhere (MOS unpublished data), follow-up rates did not differ between the 2 system cohorts for the total sample (71% vs 70% for FFS and HMO, respectively), among the elderly (both 74%), or for those in poverty (62% vs 60%). Baseline physical health scores for those followed up and lost to follow-up did not differ between FFS and HMO cohorts in analyses of the total sample or for elderly or poverty subgroups. To determine whether those lost and followed for health status outcomes had equal survival probabilities, survival was monitored for all study participants for 7 years after baseline. Survival probabilities did not differ for those followed up and those lost to follow-up. As documented in detail elsewhere (MOS unpublished data), mental health scores for those lost to follow-up were significantly ($P<.001$) lower at baseline for both FFS and HMO cohorts. The same pattern was observed for elderly and poverty subgroups, with a significant difference favoring FFS over HMO for the poverty group ($P<.05$) (MOS unpublished data). However, as documented in the tables cited in the "Results," adjusted physical and mental health scores for the follow-up samples analyzed here did not differ at baseline in comparisons between FFS and HMO cohorts within the total follow-up sample, the elderly subgroup, or the poverty subgroup.

To test whether differences in patient outcomes between FFS and HMO systems could be explained by the specialty of their regular physicians, these differences were also estimated with statistical adjustment for physician specialties. Estimates of outcomes for each system were equivalent with and without adjustment for specialty and are reported here without adjustment.

To facilitate interpretation, all tables of results include 95% confidence intervals around average change scores and all differences associated with a chance probability of .05 or less were considered statistically significant. Significance tests were not adjusted for multiple comparisons.

We hypothesized that the MOS sample would score below 50, the norm for the general population, on both measures at baseline, and they did. Because there are good arguments for hypothesizing better or worse outcomes across HMO and FFS systems over the 4-year follow-up period, we used 2-tailed tests of significance throughout.

RESULTS

Adjusted physical and mental health scores were virtually identical at baseline for patients sampled from HMO and FFS systems (Table 3). In relation to published norms for the US general population,[13] MOS patients scored at the 24th and 35th percentiles for physical and mental health, respectively, indicating substantially more physical impairment and emotional distress than experienced by the great majority of adults. During the 4-year follow-up, average changes in physical and mental health were indistinguishable between HMO and FFS systems. Physical health scores declined about 3 points in both systems, lowering the average patient to the 19th percentile at follow-up. Mental health improved slightly in both systems, raising the average to about the 38th percentile.

The MOS had sufficient statistical power to detect differences in health outcomes as small as 1 to 2 points between HMO and FFS systems of care. According to published interpretation guidelines for the SF-36 Health Survey,[13] differences of this amount or smaller are rarely clinically or socially relevant. Thus, there is a basis for confidence that an important average difference in health outcomes between HMO and FFS systems was not missed.

Analyses of change scores categorized as better, same, or worse confirmed these results for physical and mental health for the average patient. How-

Table 3.—Physical and Mental Health Outcomes for Patients Treated in Prepaid and Fee-for-Service Systems, Groups Differing in Age and Poverty Status

		Physical Health*						Mental Health*					
		Average Scores			Categorical Change, %†			Average Scores			Categorical Change, %†		
	No.	Baseline‡	4-y Δ‡	95% CI§	Worse	Same	Better	Baseline‡	4-y Δ‡	95% CI§	Worse	Same	Better
Total sample	2235	45.0	−3.0	−3.8 to −2.2	29	56	15	48.5	1.1	0.3 to 1.9	15	63	22
Service system						χ^2=1.5						χ^2=1.3	
Prepaid (HMO)	1073	44.9	−3.1	−4.3 to −1.9	30	55	15	47.9	1.2	0.0 to 2.4	14	64	22
Fee-for-service	1162	45.2	−3.0	−4.2 to −1.8	27	57	15	49.0	1.0	−0.4 to 2.4	16	63	21
Age						χ^2=14.1‖						χ^2=0.3	
Elderly	822	43.5§	−5.8¶	−7.0 to −4.6	36	53	11	50.3¶	0.7	−0.5 to 1.9	15	65	20
Nonelderly	1413	45.7	−1.9	−2.9 to −0.9	26	58	17	47.7	1.3	0.3 to 2.3	15	63	22
Poverty status						χ^2=4.6						χ^2=1.6	
Poverty	489	44.4	−3.6	−5.2 to −2.0	33	51	17	47.6	0.7	−1.1 to 2.5	17	60	23
Nonpoverty	1746	45.2	−2.9	−3.7 to −2.1	27	58	15	48.8	1.2	0.4 to 2.0	15	64	21

*HMO indicates health maintenance organization. Scores are adjusted for demographics, chronic disease, and design factors. The 4-year change scores for physical health (but not mental health) include deaths scored at 0 at 4-year follow-up.

†The χ^2 statistics for categorical change refer to the results shown below and indicate whether the patterns of change are equal across the following pair of rows.

‡Significance tests for average scores indicate whether the mean score in 1 row differed from the mean score for the other row.

§If the 95% confidence interval (CI) does not include 0, then average change scores are larger than expected by chance ($P<.05$).

‖$P<.001$.

¶$P=.01$.

Table 4.—Physical and Mental Health Outcomes in Prepaid and Fee-for-Service Systems for Elderly and Nonelderly Patients

		Physical Health*						Mental Health*					
		Average Scores			Categorical Change, %†			Average Scores			Categorical Change, %†		
	No.	Baseline (SE)	4-y Δ‡	95% CI§	Worse	Same	Better	Baseline (SE)	4-y Δ‡	95% CI§	Worse	Same	Better
Elderly	822					χ^2=19.2‖						χ^2=7.1¶	
Prepaid (HMO)	346	43.4 (0.7)	−7.0	−8.8 to −5.2	54	37	9	50.1 (0.8)	1.3	−0.5 to 3.1	14	60	26
Fee-for-service	476	43.5 (0.7)	−5.0	−6.6 to −3.4	28	63	9	50.6 (0.8)	0.2	−1.6 to 2.0	14	73	13
Nonelderly	1413					χ^2=2.3						χ^2=2.6	
Prepaid (HMO)	727	45.8 (0.5)	−1.2	−2.6 to 0.2	23	62	16	46.9 (0.6)	1.5	0.1 to 2.9	12	68	20
Fee-for-service	686	45.6 (0.5)	−2.4	−3.8 to −1.0	29	57	15	48.5 (0.5)	1.1	−0.7 to 2.9	16	64	19
Test for equivalence of differences in outcomes between prepaid and fee-for-service systems among elderly vs nonelderly subgroups		$F_{6,1518}$=2.1#				χ^2=35.6**		$F_{6,1380}$=1.3				χ^2=25.9††	

*Scores are adjusted for demographics, chronic disease, and design factors. The 4-year change scores for physical health (but not mental health) include deaths scored at 0 at 4-year follow-up.

†The χ^2 statistics for categorical change refer to the results shown below and indicate whether the patterns of change are equal across the following pair of rows.

‡Significance tests for average scores indicate whether the mean score for the health maintenance organization (HMO) group differs from the mean score for the fee-for-service (FFS) group.

§If the 95% confidence interval (CI) does not include 0, then average change scores are larger than expected by chance ($P<.05$).

‖$P=.001$.

¶$P=.03$.

#$P=.05$.

**$P<.001$.

††$P=.01$.

ever, the categorical analyses called attention to substantial variation in outcomes. Physical health scores at follow-up differed (from those at baseline) for 45% of patients; about 30% declined and 15% improved, more than would be expected due to measurement error. The reverse pattern—improvement more often than decline—was observed for mental health scores (Table 3).

Variations in Outcomes for Elderly and Poverty Groups

The average adjusted physical decline was greater for elderly than nonelderly patients (Δ=−5.8 vs −1.9; $P<.001$); 36% and 26% of elderly and nonelderly patients, respectively, scored worse at follow-up than at baseline ($P<.001$) (Table 3). Elderly patients scored higher in mental health than nonelderly at baseline ($P<.001$); nonelderly patients improved significantly over time while the elderly did not.

Both poverty and nonpoverty groups declined in physical health (Δ=−3.6 and −2.9, respectively), which are not significantly different amounts. Mental health improved significantly for nonpoverty patients but did not improve for those in the poverty group.

Differences in Outcomes by System: Elderly and Nonelderly

Although adjusted baseline scores were equivalent for elderly and nonelderly patients in comparisons between HMO and FFS systems (Table 4), changes in physical and mental health scores over time for the elderly in HMO and FFS plans were significantly different from those for the nonelderly (F=2.1, $P<.05$, and χ^2=35.6, $P<.001$ for physical health; F=1.3, $P>.05$, and χ^2=25.9, $P<.01$ for mental health) (Table 4). Physical health outcomes were, on average, more favorable for nonelderly patients in HMOs, while physical health outcomes were more favorable for elderly patients in FFS.

Although we could say with statistical confidence that the patterns of average change scores were different across HMO and FFS systems for elderly and nonelderly patients, only pairwise comparisons between categories of changes were significant for the elderly (Table 4). The analysis of change categories also revealed that physical health was much less stable over time for elderly patients in HMOs

Table 5.—Physical and Mental Health Outcomes in Prepaid and Fee-for-Service Systems for Poverty and Nonpoverty Groups

		Physical Health*						Mental Health*					
		Average Scores			Categorical Change, %†			Average Scores			Categorical Change, %†		
	No.	Baseline (SE)	4-y Δ‡	95% CI§	Worse	Same	Better	Baseline (SE)	4-y Δ‡	95% CI§	Worse	Same	Better
Poverty	489					χ^2=4.1						χ^2=4.3	
Prepaid (HMO)	295	43.3 (0.9)	−4.0	−6.2 to −1.8	32	58	9	47.2 (1.0)	−0.4	−3.9 to 3.1	14	71	14
Fee-for-service	194	45.1 (0.8)	−3.3	−5.7 to −0.9	36	46	18	47.9 (0.8)	1.3	−1.2 to 3.8	17	57	26
Nonpoverty	1746					χ^2=2.34						χ^2=2.59	
Prepaid (HMO)	879	45.3 (0.5)	−2.2	−3.6 to −0.8	24	62	13	47.9 (0.5)	1.4	0.2 to 2.6	11	70	18
Fee-for-service	867	45.1 (0.4)	−3.4	−4.6 to −2.2	30	57	12	49.5 (0.5)	1.0	−0.8 to 2.8	16	66	18
Test for equivalence of differences in outcomes between prepaid and fee-for-service systems among poverty vs nonpoverty subgroups		$F_{6,1518}$=2.7‖				χ^2=24.2¶		$F_{6,1380}$=4.2#				χ^2=23.0**	

*Scores are adjusted for demographics, chronic disease, and design factors. The 4-year change scores for physical health (but not mental health) include deaths scored at 0 at 4-year follow-up. HMO indicates health maintenance organization.

†The χ^2 statistics for categorical change refer to the results shown below and indicate whether the patterns of change are equal.

‡Significance tests for average scores indicate whether the mean score for the HMO group differs from the mean score for the fee-for-service group.

§If the 95% confidence interval (CI) does not include 0, then average change scores are larger than expected by chance (*P*<.05).

‖*P*=.01.

¶*P*=.02.

#*P*<.001.

***P*=.03.

Table 6.—Physical and Mental Health Outcomes in Prepaid and Fee-for-Service Systems for Initially Ill Patients in the Poverty Group

		Physical Health*						Mental Health*					
		Average Scores†			Categorical Change, %‡			Average Scores†			Categorical Change, %‡		
	No.	Baseline (SE)	4-y Δ	95% CI§	Worse	Same	Better	Baseline (SE)	4-y Δ	95% CI§	Worse	Same	Better
						χ^2=10.9‖						χ^2=4.1	
Prepaid (HMO)	90	35.2¶ (0.8)	−2.0#	−5.1 to 1.1	33	45	22**	37.1 (0.9)	4.5	−1.4 to 10.4	16	55	29
Fee-for-service	126	32.1 (1.0)	5.4	2.1 to 8.7	5	38	57	37.5 (0.8)	5.9	2.2 to 9.6	16	34	49

*Scores are adjusted for demographics, chronic disease, and design factors. The 4-year change scores for physical health (but not mental health) include deaths scored at 0 at 4-year follow-up.

†Significance tests for average scores indicate whether the mean score for the health maintenance organization (HMO) group differs from the mean score for the fee-for-service group.

‡The χ^2 statistics for categorical change refer to the results shown below and indicate whether the patterns of change are equal across the following pair of rows.

§If the 95% confidence interval (CI) does not include 0, then average change scores are larger than expected by chance (*P*<.05).

‖*P*=.006.

¶*P*=.014.

#*P*<.001.

***P*=.04.

compared to those in FFS (37% vs 63%, respectively, stayed the same; χ^2=19.2, *P*<.001). The elderly treated in HMOs were nearly twice as likely to decline in physical health over time (54% vs 28%; *P*<.001) (Table 4). The difference in physical health outcomes favoring FFS over HMOs was statistically significant for elderly patients regardless of their initial health (MOS unpublished data). Physical health outcomes favoring FFS over HMOs for the elderly were also apparent in all 3 study sites (MOS unpublished data).

Average changes in mental health for elderly and nonelderly patients did not favor 1 system over the other (*P*>.05). However, analyses of mental health change categories for elderly patients favored HMOs over FFS; the elderly were twice as likely to improve in an HMO (26% vs 13% for FFS; χ^2=7.1, *P*<.03). This result was due entirely to the better performance of HMOs in 1 study site. A formal test for a statistical interaction between plan and site revealed that mental health outcomes in HMOs differed significantly across the three sites (F=2.44, *P*<.01).

Differences in Outcomes of Poverty and Nonpoverty Groups by System

As shown in Table 5, comparisons of physical and mental health outcomes across HMO and FFS systems produced different patterns of results for poverty and nonpoverty groups (F=2.7, *P*<.01, and χ^2= 24.2, *P*<.02 for physical health; F=4.2, *P*<.001, and χ^2=23.0, *P*<.03 for mental health). Only the pairwise comparisons between HMO and FFS systems for poor patients who were in ill health at baseline were significant (Table 6). Those in HMOs experienced an average decline of −2.0 in physical health; those in FFS improved 5.4 points, on average (*P*<.001). Comparison of categorical changes for poor patients in initial ill health also favored FFS plans, with 57% scoring better at follow-up in FFS versus 22% in HMOs (χ^2=10.2, *P*<.006).

To determine whether Medicaid status accounted for differences observed in outcomes for the poor, HMO and FFS systems were compared among Medicaid patients (n=216). Medicaid patients in HMOs did not differ from Medicaid patients in FFS plans in health status at baseline or in health outcomes, as documented elsewhere (MOS unpublished data), and there were no noteworthy trends. However, because of the relatively small sample of Medicaid patients, the MOS did not have sufficient precision to rule out an important difference among Medicaid patients favoring either system.

COMMENT

Limitations

Limitations of the MOS have been discussed extensively,[2-8,11] but some limitations and potential sources of bias warrant special emphasis here. Analyses of 4-year health outcomes have been a long time coming because of the many methodological challenges faced by the MOS. Do results apply to current health care? If cost-containment pressures have increased since MOS data collection ended in the early 1990s, high-risk patient groups may be at an even greater risk today. If information systems for monitoring and improving the quality of care are better now and if health promotion and disease prevention initiatives are more successful in HMOs, MOS results may not apply to current health care.

The MOS was not a randomized trial; such trials are rare in health care policy research.[18,19] Although quasi-experimental methods[20] achieved equivalent average baseline health status scores for nearly all pairwise comparisons between FFS and HMO systems of care, unmeasured risk factors could have biased estimates of differences in outcomes. Further, differences in outcomes that occurred "on the watch" of the FFS and HMO systems are not necessarily their responsibility. Structural and process differences in care beyond their control, such as arrangements for home health and long-term care, may account in part for MOS findings.

The MOS monitored outcomes in only 3 large urban cities; results should not be generalized to HMO or FFS plans in other cities or rural areas. Although the MOS represented 5 chronic conditions and many patients had comorbid conditions such as angina, back pain/sciatica, lung disease, and osteoarthritis, these patients do not necessarily represent other conditions or results of care provided by other medical specialties. All patients had a regular source of care. All patients were being actively treated when the MOS began, and only three fourths who agreed to participate were followed up longitudinally.

Two potential sources of bias in estimates of health outcomes—plan switching and loss to follow-up—were systematically studied. Patient loss to follow-up is an unlikely source of bias in comparisons of outcomes between systems because adjusted physical health scores at baseline did not differ between FFS and HMO cohorts followed within the total sample or for elderly or poverty subgroups (Tables 3 through 5). Further, all study participants were followed up through 1993 to determine their survival.[4] Seven years after baseline, those included and not included in this 4-year analysis were equally likely to have survived (MOS unpublished data).

Two of 10 HMO patients switched to an FFS plan by the end of the 4-year follow-up. Comparisons between systems could have been biased had these rates differed within elderly or poverty subgroups or had switchers experienced different outcomes than nonswitchers. However, rates of switching did not differ for elderly or poverty subgroups, and system differences in physical and mental health outcomes were indistinguishable for those who stayed in the same system, in comparison with those who switched (MOS unpublished data). Thus, it is unlikely that conclusions about system differences in outcomes were biased by switching. Because more than two thirds of patients who switched systems during the follow-up period had been in their system at least 6 years before switching, we adhered to the logic of intent to treat and analyzed patients according to the systems from which they were sampled. The finding that MOS patients were significantly more likely to switch from an HMO than to an HMO (20% vs 15%; $\chi^2=7.3$, $P<.01$) is surprising given that most MOS patients were aged 60 years or older, all were chronically ill, and financial incentives were beginning to favor HMOs over FFS during the MOS. The dynamics of switching and their implications for monitoring current health outcomes warrant further study.

Although the MOS achieved the desired statistical precision for overall HMO vs FFS comparisons, confidence intervals were too large for meaningful interpretation of some comparisons that yielded insignificant differences in outcomes. Examples include comparisons between IPAs, the fastest growing form of HMO, and staff-model HMOs; Medicaid and non-Medicaid groups could not be compared with precision, and comparisons between plans within sites were relatively imprecise, although the difference in 1 site was large enough to reach significance. (This difference would not have been significant with an adjustment for multiple comparisons.) For many comparisons, the MOS cannot rule out large differences in outcomes in either direction.

Interpretation of Results

The success of HMOs in reducing health care utilization has been documented in numerous studies.[2,19] With few exceptions, the best-designed and most recent studies show that HMOs achieve lower hospital admission rates, shorter hospital stays, rely on fewer subspecialists, and make less use of expensive technologies. Results from FFS-HMO comparisons of utilization rates in the MOS[6,11] are consistent with previous studies, and extend that evidence to the population of adults with chronic conditions, for whom health outcomes are reported here. Rarely have the same studies addressed health outcomes.[2,18,21-23]

Results from the MOS lead us to several conclusions about health outcomes for the chronically ill adults who were treated in HMO and FFS systems of care during the years of the MOS. First, similarities in health outcomes between systems previously reported[4] for the average MOS patient with hypertension or NIDDM do not appear to hold for elderly patients covered by Medicare or for those in poverty. Elderly patients sampled from an HMO were more likely (than those sampled from an FFS plan) to have a poor physical health outcome in all 3 sites studied. Second, patients in the poverty group and particularly those most physically limited appear to be at a greater risk of a decline in health in an HMO than similar patients in an FFS plan. Finally, MOS results suggest the need for caution in generalizing conclusions about outcomes across study sites. Mental health outcomes for Medicare patients differed significantly across HMOs, suggesting that their performance relative to FFS plans may depend on site.

Previous studies[21-23] that found no differences in health outcomes between FFS and HMO plans followed patients for only 1 year. Were these studies too brief to draw conclusions about health outcomes? Supporting this explanation, significant differences in health outcomes observed between the FFS and HMO systems after 4 years of follow-up in the MOS were not statistically significant after 1 year. The importance of a longer follow-up is underscored by the observation that the 4-year statistical models reported here explained twice as much of the variance in patient outcomes as did the same models in analyses of 1- and 2-year outcomes (MOS unpublished data). Thus, follow-up periods longer than 1 year may be required to detect differences in outcomes for groups differing in chronic condition, age, income, and across different health care systems.

Future Outcomes Studies

Our results raise many questions that the MOS was not designed to address. What are the "clinical" correlates of changes in patient-assessed functional health and well-being? What can health care plans do to improve outcomes, and what specific treatments have been linked to physical and mental health outcomes as measured by the SF-36 Health Survey? Adverse medical events were too rare for meaningful comparison between plans in the MOS and were monitored only during the first 2 years of follow-up.[4] However, these events were significantly related to health outcomes, as hypothesized. Declines in SF-36 physical health scores were significantly more likely among patients who experienced a new myocardial infarction, weight loss sufficient to warrant a physician visit, and chest pain sufficient to require hospitalization (MOS unpublished data). These preliminary MOS results are consistent with published studies that have linked SF-36 health scores to disease severity and to treatment response, including severity of soft-tissue injuries[24] and changes in hematocrit among chronic dialysis patients.[25] The SF-36 studies of outcomes have also linked treatment to outcomes including drug treatment for depression among the elderly,[26] total knee replacement,[27,28] heart valve replacement surgery,[29] use of aerosol inhalers in treating asthma,[30] intermittent vs maintenance drug therapy for duodenal ulcer,[31] elective hip arthroplasty,[32] elective coronary revascularization,[33] and various other elective surgical procedures.[34] Three dozen such studies using the SF-36 are cited elsewhere.[35] Identification of the clinical correlates of changes in physical and mental health status warrants high priority in outcomes and effectiveness research.[36]

Future studies should address whether variations in the quality of care explain differences in outcomes across systems. The MOS patients in HMOs reported fewer financial barriers and better coordination of services in comparisons with equivalent FFS patients.[12,36] Analyses of primary care quality criteria indicated that those in FFS systems experienced shorter treatment queues and better comprehensiveness and continuity of care and rated the quality of their care more favorably.[12,37] Do such variations in process account for differences in outcomes? Practice-level analyses in progress have linked scores for primary care process indicators[12] to 4-year health outcomes, as defined here, supporting this hypothesis. These and other associations warrant further study to determine which practice styles and specific treatments are most likely to improve health outcomes. Because many of the structural and process indicators being relied on to evaluate the quality of current health care have not been shown to predict outcomes, targeted monitoring efforts are required to discern health outcomes.

The MOS has demonstrated the feasibility and usefulness of readily available patient-based assessment tools, such as the SF-36 Health Survey, in monitoring outcomes across diverse patient populations and practice settings. The SF-36 summary measures of physical and mental health reduce the number of comparisons necessary to monitor outcomes while retaining the option of analyzing the 8-scale SF-36 health profile on which they are based. The reporting of results in change categories in terms of better, same, and worse may simplify the reporting of outcomes to diverse audiences and may make results easier for them to understand. More practical data collection and processing systems—under development—and advances in understanding of the specific treatments that improve health scores the most and the clinical and social relevance of those improvements will increase their usefulness in improving patient outcomes.[38]

Policy Implications

The MOS results reported here and previously[4] for the average chronically ill patient constitute good news for those who consider HMOs as a solution to rising health care costs. Outcomes were equivalent for the average patient because those who were younger, relatively healthy, and relatively well-off financially did at least as well in HMOs as in the FFS plans. However, our results sound a cautionary note to policymakers who expect overall experience to date with HMOs to generalize to specific subgroups, such as Medicare beneficiaries or the poor. Patients who were elderly and poor were more than twice as likely to decline in health in an HMO than in an FFS plan (68% declined in physical health in an HMO vs 27% for FFS; $P<.001$) (MOS unpublished data). An implication for future evaluations of changes in health care policies is that high-risk groups, including the elderly and poor who are chronically ill, should be oversampled when outcomes are monitored to achieve the statistical precision necessary to rule out harmful health effects.

Medicaid coverage did not explain the differences in physical or mental health outcomes observed for the poor in MOS comparisons between FFS and HMO systems. Only 1 in 5 poor were covered under Medicaid. Further, when outcomes for MOS patients covered and not covered under Medicaid were compared, there were no significant differences between FFS and HMO plans and there were no noteworthy trends (MOS unpublished data). Poverty status, as opposed to Medicaid beneficiary status, was the better marker of risk of a poor health outcome in an HMO. This is not a new finding. The Health Insurance Experiment also observed that some health outcomes were less favorable over a 5-year follow-up for low-income patients in poor health in 1 HMO compared with equivalent patients under FFS care.[18]

Final Comment

In this article, the MOS has documented variations in health outcomes for chronically ill patients that cannot be explained in terms of measurement error. For elderly Medicare patients and for poor patients, variations in outcomes during a 4-year period extending through 1990 were linked to FFS and HMO systems of care (the latter were predominantly staff-model HMOs). Other explanatory factors included practice site, suggesting that health outcomes should be monitored on an ongoing basis, by particular HMO and by marketplace. Outcomes did not differ across systems for those covered under Medicaid and could not be explained in terms of the specialty training of physicians. The contrast between results reported here for high-risk patients vs results reported previously for the average patient[4] underscore the hazard in generalizing about outcomes on the basis of averages. This is why quality improvement initiatives focus on variations rather than only on usual performance.[38] Patient-based assessments of outcomes are likely to add significantly to the evidence used in informing the public and policymakers regarding which health care plans perform best—not just in terms of price, but in overall quality and effectiveness.

Indications in the text of "MOS unpublished data" refer to 16 pages of additional documents that are available at http://www.sf-36.com on the Internet. These data are also available from the National Auxiliary Publications Service, document 05340. Order from NAPS, c/o Microfiche Publications, PO Box 3513, Grand Central Station, New York, NY 10163-3513. Remit in advance, in US funds only, $7.75 for photocopies or $5 for microfiche. Outside the United States and Canada, add postage of $4.50. The postage charge for any microfiche order is $1.50.

Collection of 4-year health outcome data and preparation of this article were supported by grant 91-013 from the Functional Outcomes Program of the Henry J. Kaiser Family Foundation, at The Health Institute, New England Medical Center, Boston, Mass (John E. Ware, Jr, PhD, principal investigator). Design and implementation of the MOS were sponsored by the Robert Wood Johnson Foundation, Princeton, NJ; the Henry J. Kaiser Family Foundation, Menlo Park, Calif; and the Pew Charitable Trusts, Philadelphia, Pa. Previously reported analyses were sponsored by the National Institute on Aging, Bethesda, Md; the Agency for Health Care Policy and Research; and the National Institute of Mental Health, Rockville, Md. Participating plans, professional organizations who assisted in recruitment, and our many colleagues who contributed to the success of the MOS are acknowledged elsewhere.[3] The authors acknowledge the thorough and constructive suggestions received from Allyson Ross Davies, PhD, Kathleen Lohr, PhD, Edward Perrin, PhD, Dana Safran, ScD, and anonymous *JAMA* peer reviewers; and gratefully acknowledge the editing and typing assistance of Orna Feldman, Sharon Ployer, Rebecca Voris, and Andrea Molina.

References

1. Group Health Association of America. *Patterns in HMO Enrollment.* Washington, DC: Group Health Association of America; June 1995.
2. Miller RH, Luft HS. Managed care plan performance since 1980: a literature analysis. *JAMA.* 1994; 271:1512-1519.

3. Tarlov AR, Ware JE, Greenfield S, Nelson EC, Perrin E, Zubkoff M. The Medical Outcomes Study: an application of methods for monitoring the results of medical care. *JAMA*. 1989;262:925-930.

4. Greenfield S, Rogers W, Mangotich M, Carney MF, Tarlov AR. Outcomes of patients with hypertension and non–insulin-dependent diabetes mellitus treated by different systems and specialties: results from the Medical Outcomes Study. *JAMA*. 1995;274:1436-1474.

5. Wells KB, Hays RD, Burnam MA, Rogers W, Greenfield S, Ware JE. Detection of depressive disorder for patients receiving prepaid or fee-for-service care: results from the Medical Outcomes Study. *JAMA*. 1989;262:3298-3302.

6. Rogers WH, Wells KB, Meredith LS, Sturm R, Burnam A. Outcomes for adult outpatients with depression under prepaid or fee-for-service financing. *Arch Gen Psychiatry*. 1993;50:517-525.

7. Stewart AL, Ware JE, eds. *Measuring Functioning and Well-being: The Medical Outcomes Study Approach*. Durham, NC: Duke University Press; 1992.

8. Kravitz RL, Greenfield S, Rogers WH, et al. Differences in the mix of patients among medical specialties and systems of care: results from the Medical Outcomes Study. *JAMA*. 1992;267:1617-1623.

9. Stewart AL, Greenfield S, Hays RD, et al. Functional status and well-being of patients with chronic conditions: results from the Medical Outcomes Study. *JAMA*. 1989;262:907-913.

10. Berry S. Methods of collecting health data. In: Stewart AL, Ware JE, eds. *Measuring Functioning and Well-being: The Medical Outcomes Study Approach*. Durham, NC: Duke University Press; 1992:48-64.

11. Greenfield S, Nelson EC, Zubkoff M, et al. Variations in resource utilization among medical specialties and systems of care: results from the Medical Outcomes Study. *JAMA*. 1992;267:1624-1630.

12. Safran D, Tarlov AR, Rogers W. Primary care performances in fee-for-service and prepaid health care systems: results from the Medical Outcomes Study. *JAMA*. 1994;271:1579-1586.

13. Ware JE, Kosinski M, Keller SK. *SF-36 Physical and Mental Health Summary Scales: A User's Manual*. Boston, Mass: The Health Institute, New England Medical Center; 1994.

14. Ware JE, Kosinski M, Bayliss MS, McHorney CA, Rogers WH, Raczek A. Comparison of methods for scoring and statistical analysis of SF-36 Health Profiles and Summary Measures: summary of results from the Medical Outcomes Study. *Med Care*. 1995;33(suppl 4):AS264-AS279.

15. McHorney CA, Ware JE, Raczek AE. The MOS 36-Item Short-Form Health Survey (SF-36), II: psychometric and clinical tests of validity in measuring physical and mental health constructs. *Med Care*. 1993;31:247-263.

16. Diehr P, Patrick D, Hedrick S, et al. Including deaths when measuring health status over time. *Med Care*. 1994;32(suppl 4):AS164-AS172.

17. *STATA Reference Manual: Release 3.1, Volume 3*. 6th ed. College Station, Tex: STATA Corp; 1993: 3-16.

18. Ware JE, Brook RH, Rogers WH, et al. Comparison of health outcomes at a health maintenance organization with those of fee-for-service care. *Lancet*. 1986;1:1017-1022.

19. Manning WG, Leibowitz A, Goldberg GA, Rogers WH, Newhouse JP. A controlled trial of the effect of a prepaid group practice on use of services. *N Engl J Med*. 1984;310:1505-1510.

20. Cook TD, Campbell DT. The design and conduct of quasi-experiments and true experiments in field settings. In: Dunnette MD, ed. *Handbook of Industrial and Organizational Psychology*. Chicago, Ill: Rand McNally College Publishing Co; 1976: 223-326.

21. Lurie N, Moscovice IS, Finch M, Christianson JB, Popkin MK. Does capitation affect the health of the chronically mentally ill? results from a randomized trial. *JAMA*. 1992;267:3300-3304.

22. Retchin SM, Clement DG, Rossiter LF, Brown B, Brown R, Nelson L. How the elderly fare in HMOs: outcomes from the Medicare competition demonstrations. *Health Serv Res*. 1992;27:651-669.

23. Clement DG, Retchin SM, Brown RS, Stegall MH. Access and outcomes of elderly patients enrolled in managed care. *JAMA*. 1994;271:1487-1492.

24. Beaton DE, Bombardier C, Hogg-Johnson S. Choose your tool: a comparison of the psychometric properties of five generic health status instruments in workers with soft tissue injuries. *Qual Life Res*. 1994;3:50-56.

25. Beusterien KM, Nissenson AR, Port FK, Kelly M, Steinwald B, Ware JE. The effects of recombinant human erythropoietin on functional health and well-being in chronic dialysis patients. *J Am Soc Nephrol*. 1996;7:1-11.

26. Beusterien K, Steinwald B, Ware JE. Usefulness of the SF-36 health survey in measuring health outcomes in the depressed elderly. *J Geriatr Psychiatry Neurol*. 1996;9:1-9.

27. Kantz ME, Harris WJ, Levitsky K, Ware JE, Davies AR. Methods for assessing condition-specific and generic functional status outcomes after total knee replacement. *Med Care*. 1992;30(suppl 5):MS240-MS252.

28. Hawker G, Melfi C, Paul J, Green R, Bombardier C. Comparison of a generic (SF-36) and a disease-specific (WOMAC) instrument in the measurement of outcomes after knee replacement surgery. *J Rheumatol*. 1995;22:1193-1196.

29. Phillips RC, Lansky DJ. Outcomes management in heart valve replacement surgery: early experience. *J Heart Valve Dis*. 1992;1:42-50.

30. Okamoto LJ, Noonan M, Kirchdoerfer LJ, Boyer JG, Kellerman DJ, Saiers JA. Quality of life in patients with severe asthma: baseline health profile and effects of fluticasone propionate aerosol. *Ann Allergy Asthma Immunol*. 1996;76:1-7.

31. Rampal P, Martin C, Marquis P, Ware JE, Bonfils S. A quality of life study in five hundred and eighty-one duodenal ulcer patients. *Scand J Gastroenterol*. 1994;29(suppl):44-51.

32. Stucki G, Liang MH, Phillips C, Katz JN. The Short Form-36 is preferable to the SIP as a generic health status measure in patients undergoing elective total hip arthroplasty. *Arthritis Care Res*. 1995; 8:174-181.

33. Krumholz HM, McHorney CA, Clark L, Levesque M, Baim DS, Goldman L. Changes in health after elective percutaneous coronary revascularization: a comparison of generic and specific measures. *Med Care*. 1996;34:754-759.

34. Temple PC, Travis B, Sachs L, Strasser S, Choban P, Flancbaum L. Functioning and well-being of patients before and after elective surgical procedures. *J Am Coll Surg*. 1995;181:17-25.

35. Shiely J-C, Bayliss MS, Keller SD, Tsai C, Ware JE. *SF-36 Health Survey Annotated Bibliography: First Edition, 1988-1995*. Boston, Mass: The Health Institute, New England Medical Center. In press.

36. Roper WL, Winkenwender W, Hackbarth GM, Krakauer H. Effectiveness in health care: an initiative to evaluate and improve medical practice. *N Engl J Med*. 1988;319:1197-1202.

37. Rubin H, Gandek B, Rogers WH, Kosinski M, McHorney C, Ware JE. Patient's ratings of outpatient visits in different practice settings: results from the Medical Outcomes Study. *JAMA*. 1993; 207:835-840.

38. Davies AR, Halpern R. *Health Care Outcomes: An Introduction*. Irving, Tex: Voluntary Hospitals of America Inc; 1993.

Quality
Special Needs Population
Patricia MacTaggart
July 15, 1997

Value-based, beneficiary-centered purchasing:
* access
* accountability
* quality services
* afford ability
* enrollee satisfaction
* responsive to individual health needs

Federal-state partnership:
* communication
* coordination
* collaboration

Evaluating services:
* point of view of the beneficiary
* standardized performance measures for provider feedback and quality improvement

Approach:
* defining where we want to go
* completing an inventory of what is currently being done/not done
* how the pieces fit
* how organizationally make it work

Components of value-based, beneficiary-centered purchasing quality strategy:
* who are we purchasing for: eligibility, outreach, enrollment
* who to contract with: purchasing tools
* what to contract for
* where and when to contract: contractor specifications
* how to monitor: quality oversight system

Priority: developing and implementing a Medicaid value-based, beneficiary-centered purchasing strategy

TOOLS USED

Contracting Options: selective contracting - centers of excellence

Monitoring Tools: performance measurement

CAHPS: consumer assessment accessibility, waiting times, ease in seeing one's chosen physician, courtesy

HEDIS: MH/CD, pediatric networks, dental, asthma, beta blockers, low-birth weight babies and AIDS in testing, provider credentialing

External Quality Assurance Reviews: focus studies and medical record reviews

QARI

Grievance/complaint monitoring

Consumer advocates at local level

Performance based contracts: special provisions for special populations (ADA)

Enrollee Education

Issues, Barriers: Limited FFS data/information - no baseline

MH/CD state of art of performance measurement

Chronic care: variable community standards
Medicaid coverage issues

THE STATE OF THE STATES

TUESDAY, JULY 22, 1997

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The forum met, pursuant to notice, at 9:30 a.m., in the Dirksen Senate Office Building. Ms. Susan Christensen, Public Policy Fellow, presiding.

OPENING STATEMENT OF MS. SUSAN CHRISTENSEN

Ms. CHRISTENSEN. Good morning. I am Susan Christensen, a fellow with the Aging Committee. I would also like to introduce Hope Hegstrom and LaVita Westbrook from our staff, and Ken Cohen from Senator Breaux's staff. Is there anybody else from Senator Breaux's staff? [No response.]

This series of forums developed after the Committee had a hearing about people with chronic conditions who are dually eligible for Medicaid and Medicare. The issues we encountered as we worked on that hearing could be divided in many ways. We divided them roughly into four main themes which are the topics of these four forums.

At the first forum, we got a picture of what it means to be a person with special needs. The theme of the second forum was the ability of the current managed care industry to deliver health care effectively to individuals with a wide variety of specialized needs. The forum last week addressed quality and outcome measures.

Today we have five people to help us look at the process of State contracting for systems of care for their Medicaid populations, especially beneficiaries who have special needs—we are hoping we are going to have five people.

Our panelists will each give a short presentation, and then we'll have time for questions and discussion. Keep track of your questions, and we'll have time for them after the presentations.

Ultimately, the Committee plans to publish the information generated by these forums and make it available to Congress and the public.

At this time, the Committee would like to thank Bill Scanlon from GAO and his staff, Sally Kaplan and Kathy Allen for their assistance in all of these forums, helping us to articulate our concept and coordinate these presentations.

Once again, I have to thank LaVita Westbrook, who is the organizer of all the details; without her, these forums would not happen.

Our first panelist is Bill Scanlon, who is Director of the Health Financing and Systems Issue Area at the U.S. General Accounting Office, or GAO. He has been engaged in health services research since 1975. Before joining GAO in 1993, Dr. Scanlon was co-Director of the Center for Health Policy Studies and an associate professor in the Department of Family Medicine at Georgetown University. His research has focused in particular on the Medicare and Medicaid programs, especially provider payment policies, and the provision and financing of long-term care services.

Jane Horvath is Director of Special Projects for the National Academy for State Health Policy, where she oversees the Academy Medicaid Managed Care Resource Center activities and staff. She recently developed the 1997 edition of "Medicaid Managed Care: The State of the Art," a guide for States which examines Medicaid managed care quality issues as they affect low-income mothers and children and children in foster care. Ms. Horvath also recently completed a 50-State survey and study of State regulation and oversight of prepaid managed care entities entitled, "Emerging Challenges in State Regulation of Managed Care."

Barbara Shipnuck is Deputy Secretary for Health Care Policy, Finance and Regulation in Maryland and was appointed in January 1996. She oversees the Maryland Medicaid System.

Stephen Somers established the Center for Health Care Strategies, Inc., a nonprofit organization affiliated with Princeton University's Woodrow Wilson School of Public and International Affairs. Dr. Somers is also Director of the Robert Wood Johnson Foundation's Medicaid Managed Care Program, an initiative designed to make managed care work, especially for Medicaid beneficiaries with chronic health and social problems. Previously, he was Associate Vice President at the Robert Wood Johnson Foundation.

Peggy Bartels is Director of the Wisconsin Medicaid Program's Bureau of Health Care Financing, Division of Health. In this capacity, she is responsible for all aspects of administration of the Medicaid Program in the State of Wisconsin. Ms. Bartels also manages the Wisconsin Medicaid HMO program which has been regarded as one of the top programs in the country and will serve 230,000 AFDC eligibles by early 1997. Previously, Ms. Bartels was an associate at Broyderick and Associates and Deputy Director of the Wisconsin Medicaid Program.

Thank you all for coming today. We appreciate that you have taken the time and effort to be with us.

I'm going to turn this over to Bill, and I think we'll go right down the table. Thank you.

STATEMENT OF WILLIAM J. SCANLON, DIRECTOR, HEALTH FINANCING AND SYSTEMS ISSUE AREA, U.S. GENERAL ACCOUNTING OFFICE, WASHINGTON, DC

Mr. SCANLON. Thank you very much, Susan. It has been a pleasure and privilege for us to be participants in this series, and we want to commend the Aging Committee's majority and minority staffs for putting together this series on a very important topic, and doing it in such a thorough and comprehensive way.

I think that, having been at all four forums, I have the ability to provide a little continuity in this series, and I would like to talk a little bit about some of the issues that we have heard repeatedly over the course of these three and now this fourth session.

One important theme that has emerged is the issue of the readiness of all of us to be able to provide managed care for people with special needs. It is a source of concern, but while it is a source of concern, at the same time, I think we have not talked about the issue of how important or how beneficial it might be able to provide managed care for people with special needs. I think this is because we recognize from a State perspective, with Medicaid programs having about one-third of the beneficiaries being either elderly or disabled, yet they account for about two-thirds of the spending, that the prospect of managed care as a means of controlling the growth of spending is a very positive situation.

From the beneficiaries' perspective, in the first session particularly, we heard about the incredibly complex and expensive needs of individuals with special needs. The idea of individuals whose capacity has been so compromised by different conditions, difficulty in navigating the fee-for-service system makes it obvious that their potential for benefiting from good management of care is something that we would like to be able to provide to them.

At the same time, while we can see some of the advantages, we can see where we have a fair amount of pessimism about our ability to actually implement managed care for people with special needs, primarily based on our inexperience—inexperience on the part of virtually all the major players.

In the industry itself, HMOs have typically been dealing with a working-age population that generally does not have the very significant and complex needs of the populations that we have been talking about.

States have largely not been using managed care for their disabled populations. As we indicated in our review last year, there were 17 States that had implemented any form of capitated managed care for persons with special needs. Only 6 of those had mandatory programs, and only one of those had more than 3 years' worth of experience.

We also think there has been a lack of support or experience on the part of the policy analysis community. We, the people that I work with all the time and my colleagues before I joined GAO, have provided the kind of information that would be helpful to States and managed care organizations in terms of planning a program for people with special needs. Things like how to design networks that really need to rely on specialists, how to deal with the risk adjustment issue in plan payments, and how to deal with appropriate oversight to ensure that there is the right kind of quality of care that is being delivered and paid for.

That pessimism, though, I think needs to be taken with the appropriate perspective. If we are going to build knowledge, we are going to need to build it through experience, and I think we can have an experience that is satisfactory if we do it in a way that we emphasize flexibility, we emphasize tailoring the programs for the populations that we want to service, and if we remain attentive to what is happening in the programs that we are undertaking.

There are five areas that I would like to emphasize. Some of them, we have touched on in the other sessions, and others I think are appropriate to bring to this final session and should be addressed as we think about managed care for populations with special needs.

The first of these is that the design or structure of these programs should probably be a negotiated design. As we have talked to people in the States, both State officials and representatives of persons with special needs, it is clear that there is no "right" answer to many questions, such as how do you structure a network of specialists, what kinds of rules of access do you have for specialists, what definition should you use in terms of what is a medically necessary service, what are the boundaries between what a managed care organization is supposed to provide and the other services a person may need that Medicaid may fund or that other sources may be funding. Since there is no right answer, you need to come to an agreeable answer and an answer that you recognize the necessity to adjust over time as your experience dictates.

A second important area is how you go about enrollment. I think a major aspect of this issue is that there be a fairly generous policy of allowing people to opt out when it is inappropriate for them to move into a managed care situation. It could be because of their family circumstances, their condition; it could be because of the geographic location. There is not going to be a managed care organization that is going to be able to serve everybody with special needs in every location they necessarily live in, and it may be that we then need to rely on fee-for-service, or fee-for-service with some type of assistance in the form of case management to serve individuals in those circumstances.

It is also important to the enrollment process that we provide individuals with adequate information about what managed care entails, how they are going to get services, how they are able to voice complaints about their services if they are not receiving the necessary services.

It is also important that we provide for continuity of care. I think we talked about this in the second session. It is a critical issue that people who have special needs have existing relationships with providers, and to move them into a managed care organization with potentially a different network of providers, steps must be taken so that the care that they are receiving is not interrupted. It may be fine for many of us to join a managed care organization and to not make contact for a month or 2 months or even longer, but it is not as often the case that it is acceptable for persons with special needs to have a gap in the services that are available to them.

A third area is the issue of providing assistance with access. Case management is an obvious service that individuals with complex and expensive needs may benefit from in terms of navigating the myriad number of providers that they are going to need to see. We noted in the second session that most Medicaid contracts, in the review of contracts that was done by George Washington University, did not explicitly address case management. If you don't address it in your contract, you are not going to be able to hold plans accountable for providing it.

There is also the proverbial question with case management, which is to whom is the case manager accountable. We used to talk about case management in terms of fee-for-service as being the gatekeeper, and we also wondered what were the incentives for this case manager to really be an effective gatekeeper. Now that we have created an incentive through capitation for the organization to in some sense be the gatekeeper, and we are asking the organization to hire a case manager to advocate for access to patients, the question is who is that case manager going to be accountable to—the organization or the patient. There is a tension there, and it is not clear how the incentives work out.

Besides a case manager for individuals, there is also the issue of ombudsmen and grievance appeal procedures that exist within managed care organizations. Each of these needs to be emphasized, and the awareness of the information about these procedures needs to be widely disseminated so that individuals have the knowledge to know how they can address concerns or complaints about their services.

The fourth area that I think is important is the issue of stratified oversight. What we are talking about with people with special needs is a very, very small segment of the population. To look at managed care organizations' performance in terms of medical reviews and analyses of encounter data, satisfaction surveys, and looking at that through a random sample is not going to capture enough of the individuals with special needs to be able to know whether those individuals are being well-served. We need to have special samples of those kinds of individuals.

The last area that I think is important is that we need to be concerned about how we pay our managed care organizations. Pure capitation creates the strongest incentives to control the use of services and to profit from not delivering services. Since we are not certain about what is the appropriate level of services, it may be much better to think about dampening the incentive for underservice by establishing limits on the amount of profit that organizations can make from serving persons with special needs as well as protecting those organizations from the adverse selection that may occur when too many individuals with special needs join their organization and the cost of serving them exceeds the capitation payments.

We need to do all of these things, and it is important that we learn from all of these things. It is an expensive thing to tailor a program and to be attentive to how well it is working. What we are hoping is that in the future, we will have a much better knowledge base as to what works and what does not work, so that we can design programs that have more structure to them than we can today, but we can still have confidence that they are going to operate effectively.

Thank you.

Ms. CHRISTENSEN. Thank you, Bill.

Welcome, Barbara.

STATEMENT OF BARBARA SHIPNUCK, DEPUTY SECRETARY FOR HEALTH CARE POLICY, FINANCE AND REGULATION, STATE OF MARYLAND DEPARTMENT OF HEALTH AND MENTAL HYGIENE, BALTIMORE, MD

Ms. SHIPNUCK. Good morning. I am Barbara Shipnuck. I am the Deputy Secretary for Health Care Policy, Finance and Regulation for the State of Maryland, and we are the newest 1115 to come on line.

Unlike some States, we chose to go statewide and to include both our disabled and traditional moms' and children's welfare population in our demonstration project. The demonstration's official start date was on June 2; our first day of capitation and services was July 1. As of yesterday, of the 330,000 people we plan to enroll in the 5-month rollout phase between June and November, we had 89,000 individuals enrolled.

The guiding principles behind the development of Maryland's 1115 waiver application and the program we designed was to place our Medicaid recipients into what we call a "medical home"; this was the guiding principle of our secretary, Marty Wasserman, whom some of you know from his background as a local health officer and his presence in many of the national associations. So he was determined that not only would we create a medical home for these individuals and, as Mr. Scanlon pointed out, that's one of the areas where you particularly have to pay attention if you are dealing with special needs populations—but he was also determined that we combine the Medicaid impetus and the financing concerns that we all share with the health paradigms that often are overlooked when you try to roll into just a Medicaid managed care program without the tie-ins to the milestones that your State is facing and the targets for the year 2000 without reassessing what your strengths and weaknesses are and without working very closely with your public health comrades in your department or your State structure.

In Maryland, we may be unique in terms of the way our department is structured, because our public health and Medicaid are under one department, and yet our eligibility and human resources and environmental health are in a separate department. So we tend to have basically two branches in the department that the Secretary supervises, and those are the Medicaid and the public health sides. So there was a tremendous amount of linkage and collaboration as we went through the process at the department.

But what Maryland did, which we are very proud of, and it is now being held up as a model for States that are beginning to enter the arena, was to have a very, very extensive public process in the development of our program from the very, very beginning. So, unlike some States where the State itself designed the program and then took it out for review or submitted it to HCFA and then got the public comments, Maryland worked with the various constituencies from the very beginning.

So during 1995, there was a committee that continued to grow because different constituencies, advocacy groups, individuals, and legislators wanted to participate, and at the final count, there were 132 individuals on this committee who reviewed the various proposals and steps for what kind of waiver application the State of

Maryland ought to submit that would be specific to the kinds of needs of the population, the concerns we had, and our desire to have it cover a variety of populations.

The target milestone dates I would just point out to you because in the end, we had a very quick process, although in the beginning, we had a very extensive public process. Throughout 1995, we had meetings throughout the State of Maryland discussing various proposals and ideas for a waiver. In May 1996, following legislative action which approved the department implementing the waiver as designed in this extensive public hearing process, a waiver application was submitted to HCFA. In December 1996, the State of Maryland developed the regulations and took them through the legislative process.

Mr. Scanlon alludes to the fact that all of the protections that you want for your population should be in the contracts that you have with your managed care organizations. If you want case management, that needs to be in the contracts. Maryland's is a little different system from most of the other States. Everything we want to hold people accountable for has got to be in absolutely publicly discussed and publicly adopted regulations. So our contracts tend to be much shorter and safer than a lot of other States, because our contracts reference everything in the regulations. So that for Maryland, if you were to look at what we are requiring and how we hold people accountable, you need to ask for our regulations rather than just the short contract document between the State and the managed care organization, and the managed care organizations are responsible for everything in the regulations.

We went through the regulatory process last summer, and in October, we had our waiver application approved by HCFA, so that we were able to begin to move forward. We chose June 2 as our beginning enrollment date. That gave us about 6 months to go through the process of reviewing managed care organizations, making certain they met all of the requirements of the regulations, and to begin their service provision on July 1.

At the time we began on June 2, we had six approved managed care organizations; today, we have eight. Maryland again is a slightly different process than some other States. One, we did not do competitive bids because we wanted to protect the historic relationships of providers, and we did not want to see any historic providers excluded from the process by having losing bidders versus winning bidders, and so therefore some of the provider networks excluded.

Second, the department was actually granted a unique authority so that where an historic provider is unable by his or her own ability to obtain a contract with a managed care organization, the department actually has the authority to assign that provider to a managed care organization. Because our emphasis and concern was on continuity of patient relationship and continuity of care, we wanted to be certain that our recipients could continue to choose their provider and the organization that provider belonged to.

We went through a very extensive process of holding our managed care organizations accountable, of having the rates be publicly known, and any organization willing to accept the State's capitation rate and meeting all the requirements in the regulations was certified to participate in the program. So we didn't have an open and shut window, and we continue to review applications as they come in.

Following the extensive public input process that I described and the various advisory groups that were formed to go through that, as we have now started the implementation phase, we have made that as much of a public process. The Medicaid advisory committee includes five legislators among its membership of 25; the various advocacy groups are represented, and in addition to that, we have continuing and constant working groups that meet to talk about the various aspects of implementation. We have a Special Needs Advisory Council for the children whom we are most concerned about in our target population for discussions today, to make certain they have the access that is promised and that we want to hold the managed care organizations accountable for. We have groups that meet on data, we have groups that meet on—I met yesterday with all of the federally qualified health centers in the State of Maryland to discuss their various concerns about meeting the needs of their constituencies and some of the enabling services that they want to be certain are provided.

So we continue to monitor the implementation to make sure that the promise of Health Choice is carried through, and we do that in conjunction, as I said, with our public health colleagues to make certain that we keep in mind all of the various issues for improving the health status of the communities that we serve, because to do a demonstration project just for the sake of saving money or just for the sake of proving that a State can in fact manage with a managed care system their Medicaid population was not the goal of the State of Maryland. We want a better health outcome for the recipients that we move into managed care.

We think many of the Medicaid population, including those folks in Medicaid who have special needs, have if anything been underserved in the past, whether it has been in Medicaid fee-for-service, whether it is has been in Medicaid primary care case management which we have in Maryland, or whether it has been through traditional HMO capitation, because they don't come in to seek the preventive care, they don't come in for the ongoing checkups, whether it is for a special condition, whether it is for prevention, or whether it is for immunization. So we have written all of those in as requirements and goals in our system.

We have also paid special attention to how we have designed our mental health system. We pay special attention to how we work with our AIDS administration in the protections and services for people with AIDS. We have worked closely with our Alcohol and Drug Administration and with our local health officers. Those are all organizations that are on the public health side of our department.

So to move on to the heart of today's discussion how we have worked with special needs population in the design and now the implementation of Health Choice, we started by clearly defining seven special needs populations that would require special attention and special services by any and all of our managed care organizations, including case management. Mr. Scanlon mentioned those needed to be referred to in the contract. Those are clearly defined by us in our regulations, so there is no equivocating about whether you have responsibility for case management for special needs populations in Maryland.

The seven populations that we defined were: the physically disabled; pregnant and post partum women; people diagnosed with HIV/AIDS; children with special health care needs; the developmentally disabled; the homeless, and persons in need of substance abuse treatment. So all of those populations are called out for additional services and responsibilities to the managed care organization.

Our approach to ensuring quality medical care for these special needs populations has several components to it. The first is around the way in which we do capitation. As you all know, often, managed care organizations claim that they cannot afford to take care of people with special needs because of the way capitation is defined, and so they self-select or they cause people to disenroll. That was actually the experience in Maryland in our voluntary program, where our managed care organization and an individual could disenroll—a managed care organization could urge an individual to disenroll. Currently in Maryland, an individual selects a managed care organization, and that managed care organization must accept the patient. They have no right to refuse someone because of their prior physical condition or their known medical history.

What we have tried to do to make that feasible across our MCOs is that we have built into our capitations the cost of care based on previous medical history. So we actually have two sets of capitation rates. Where we do not have a medical history for an individual, we base the capitation on age, gender, eligibility categories—so there is a difference between SSI and other eligibility categories—and for the city of Baltimore, we have a geographic adjuster because the cost of care is higher. For those individuals—and currently that is more than one-third of our population and will grow over time as we have experience—for more than one-third of our population, we use ambulatory care groupings, which was designed by Professor Jonathan Weiner at Johns Hopkins School of Public Health, someone whom we are familiar with and have been able to work closely with, and that rate adjustment is based on what the expected use of care is for a specific individual. So that when that individual chooses a managed care organization, the dollars that should be able to support that individual's medical care go to that organization. It is a way of making certain that more dollars flow to an organization taking care of people with greater health care needs than to one that does not. We have done that.

In addition, we did design a stop-loss program to make it feasible for managed care organizations to take care of individuals even at the early part of the program. I would be happy if we have time at the end to go into this a little bit more extensively, because I know our time is limited for presentations.

Our managed care organizations must provide the full range of medically necessary services, from primary care to specialist care to ancillary care to case management, and our local health departments have been given specific grants to help with transportation so that people can get to there appointments and get their appropriately.

Managed care organizations must have the necessary infrastructure in place to serve our special needs population, and that includes an emphasis on case managers and care coordinators. They also must have individuals who are specifically designed as special needs coordinators, so that a person is responsible for monitoring the care and the coordination of services for our various special needs populations.

Managed care organizations must have developed appropriate referral protocols and submitted those during the application process for review so that we can ensure that referrals will be made appropriately for specialty care in these populations.

We have ongoing departmental meetings between our nurse coordinators at the department and our managed care organization special needs coordinators. We have consumer advisory boards that are required by each managed care organization, one-third of whose membership must come from the population with special needs that is enrolled in that managed care organization, and any and all complaints that come into that managed care organization through their own internal grievance procedures must be reported to their consumer advisory board, and those become the subject of a legislative report annually. That is in addition to the central grievance hotline procedures that the department has and in addition to our onsite reviews of medical records and others that we do. We continue to have extensive outreach and education campaigns through our advocacy groups and with various groups in the community.

So we have built in those various approaches in attempting to ensure that quality medical care will be obtained by all of our special needs recipients.

The second level of that is that we have built in special protections for quality review and monitoring as we go through implementation and on an ongoing basis. Our department has an oversight role. We have both internal and external quality assurance requirements. We have an external quality review organization contract that will be doing extensive monitoring, but clearly only after you have phased in your entire program and generally on a yearly basis. However, we have nurse teams that actually go out and review medical records and actually look at specific indicators. This year, we are looking at child asthma, we are looking at sickle cell anemia, and we are picking out a full target that will be defined by our Special Needs Children Advisory Group, one where we can actually go in and check the medical records and make sure the referrals were made, [inaudible] to the time lines, and see that the care was actually delivered.

We have lengthy reporting requirements through their encounter data. That will start one quarter after the program begins. We have our focused clinical reviews. We have an extensive ombudsman program in place that we have asked our local health departments to perform. So an individual who calls in with a complaint can be referred to their local health department, which will work with the managed care organization to attempt to resolve the care issues. The local health departments are empowered to do everything except order the care delivered. Our department, however, can order the care delivered.

To get to that kind of situation, a managed care organization must deliver the care. They can appeal whether that decision was appropriate, but only after the care was delivered, at which point then the question becomes who pays for it—was the department in error, so we pay for it because we exceeded the bounds of our authority, or do they pay for it. But the care gets delivered first, and then the question involves, really, a grievance about payment.

We have a enrollee action hotline for complaints, we have provider hotlines, and we have a number of different ways to measure whether the program is working successfully, including satisfaction surveys.

We have one small carve-out that I want to bring to your attention and then close my comments. Given the special needs populations that we serve in Maryland, we defined several diagnoses that have very small numbers of cases statewide and cost a great deal of money. We call these rare and expensive cases, so we have a rare and expensive case management program. Those folks are not enrolled in managed care organizations.

There is a separate and specific case management arrangement for dealing with their care. Their care is paid for fee-for-service, and we will monitor over time whether we need to expand the number of diagnoses in that category. That covers between 2,000 and 3,000 people statewide in Maryland of the 330,000 individuals eligible for health choice. Most of the diagnoses are pediatric spina bifida, pediatric AIDS, but we have a few that go across age lines, and that is one of the areas where I know a lot of States are looking to see how we fare in terms of our proposal.

If I could leave you with anything this morning, I think there were two very clear lessons learned from the way Maryland developed our managed care proposal for Medicaid and we move through the implementation.

First and foremost, having a very extensive and open public process along the way at the very beginning to let you know what your pitfalls are up front, let you know what areas of the program to eliminate to start with, let you bring people on line to be your advocates and your supporters as you then go through a legislative process, and it fosters acceptance. So for those States or those advocacy groups that are working with various States, I would say that having a public process to start with is just an absolute essential for making sure that you come out with a successful program at the end.

Second, making your provision of care to the Medicaid population with your public health key indicators really can become a measure of success because managed care should not be managed care just for the sake of going on the bandwagon for the buzzword of how we pay for things in the 1990's, but managed care really ought to lead to better care for an underserved population that provides for better health throughout the community.

To me, those would be the measures of success for any demonstration project.

Thank you very much.

[The prepared statement of Ms. Shipnuck follows:]

State of Maryland
Department of Health and Mental Hygiene
Parris N. Glendening, Governor - Martin P. Wasserman, M.D., J.D., Secretary

Presentation of Barbara Shipnuck
Deputy Secretary for Health Care Policy, Finance and Regulation
State of Maryland

Before

The U.S. Senate Special Committee on Aging
Forum on Medicaid and Managed Care
July 22, 1997

For More Information Contact:
Stephanie Kennan, Office of
Governmental Affairs (410) 767-6459

201 West Preston Street - Baltimore, Maryland 21201
TDD for Disabled - Maryland Relay Service (800) 735-2258

Healthy People in Healthy Communities

Outline of Presentation for Deputy Secretary Barbara Shipnuck - DHMH
Panel on the State of the States
July 22, 1997

I. Introduction & General Overview of HealthChoice

- June 2, 1997 official start day
- 330,000 recipients over 5 month phase in
- As of July 17, 53,020 recipients have been voluntarily enrolled into HealthChoice
- Guiding principles and "Medical Home" concept
- Inclusion of Special Needs Populations

II. Structure of DHMH

A. One Department - Public Health and Medicaid under one Department (DHMH)

(Tie in to Local Health Departments)

B. Linkage -This structure has greatly contributed to the development of HealthChoice and helped to link managed care organizations (MCOs) with traditional public health/local health dept.

III. Process of HealthChoice - Open and Inclusive

A. Legislative Background

- 1995 - General Assembly directed DHMH to investigate use of managed care for Medicaid
  (Very public process)

- 1996 - General Assembly passed SB 750, directing DHMH to implement an 1115 waiver from HCFA

(Very specific requirements in the laws including separate mental health systems)

B. Development of 1115 Waiver - Record Setting Time

* 1995	130 member task force met throughout 1995 to develop the proposal
* May, 1996	Waiver application submitted to HCFA
* Summer, 1996	Regulations developed
* October, 1996	Waiver application approved by HCFA
* November, 1996	HealthChoice Regulations approved by the Legislature
* June 2, 1997	Enrollment begins
* July 1, 1997	Services Begins

C. Development of HealthChoice - serves as a "Model" for other states

Extensive Public Input - State-wide Public Hearings and Recipient Forums
Public Advisory Groups representing all Medicaid sub-populations - Advocates, Medicaid Providers, Medicaid Recipients involved (weekly meetings)
Multiple Work Groups - Mental Health/ASO, GME, substance abuse, REM, Special Needs Children
Medicaid Advisory Committee (monthly meetings)
Legislative Hearings - Senate Finance, Environmental Matters, AELR

D. Contributions of Public Health Administrations (collaboration)

Mental Hygiene Administration
AIDS Administration
Alcohol and Drug Abuse Administration
Local Health Officers and Local Health Departments

IV. Product of HealthChoice

A. Special Needs Populations Included in HealthChoice - (DEF.) Individuals that are:

(1) physically disabled
(2) pregnant/postpartum women
(3) diagnosed with HIV/AIDS
(4) children with special health care
(5) developmentally disabled
(6) homeless
(7) in need of substance abuse treatment

B. Approaches to Ensure Quality for Special Needs Population

- Cost of care is built into capitation rates, based on previous medical history (if known)
- MCOs must have the necessary infrastructure in place to serve Special Needs Populations
- MCOs are accountable for providing quality care to all recipients
- DHMH has oversight role. Internal and external QA required.
- MCOs must provide full range of medically necessary services (primary care, specialists, ancillary services)
- MCOs must have referral protocols in place to ensure referrals for specialty care
- Monthly reporting requirements (Encounter Data)
- Ongoing Departmental meetings with MCOs
- MCO Consumer Advisory Boards
- Extensive educational/outreach campaign

C. Special Protections for Special Needs Populations

- Special Needs Coordinator
- Case Management - All seven groups require separate case management
- Focused Clinical Reviews - e.g. asthma, sickle cell anemia
- Ombudsman Program at Local Health Department Level
- Grievance Procedures, Consumer satisfaction surveys
- Complaint Hotlines - (1) HealthChoice Enrollee Action Line, (2) Provider Hotline

D. Special Needs Advisory Council

V. Lessons Learned Along the Way

- Public process eased way and fostered acceptance

- Link with public health key in success of HealthChoice

HealthChoice Fact Sheet

On October 30, 1996 the U.S. Department of Health and Human Services (HHS), granted Maryland's request for authority under Section 1115 of the Social Security Act to implement a statewide health care reform research and demonstration project. The Maryland Medicaid Managed Care Program, known as HealthChoice, reflects the direct participation of 125 representatives from health care provider and consumer groups, 1750 private citizens who participated in seventeen public hearings across the state and several groups of Medicaid recipients who were involved in focus groups and consumer forums.

On November 8, 1995, the Maryland General Assembly Joint Committee on Administrative, Executive and Legislative Review approved emergency regulations to begin the actual implementation of HealthChoice. The Maryland Department of Health and Mental Hygiene (DHMH) will begin to enroll recipients into HealthChoice Managed Care Organizations (MCOs) in June 1997. This will be the beginning of a five-month phase-in enrollment process for almost 300,000 Medicaid recipients in Maryland.

Guiding Principles For HealthChoice

The HealthChoice program is based on several underlying principles which are designed to make it an unique Maryland program. These principles are:

* Patient-focused -
designed to meet the needs of people and to provide a single medical home for all members is "consumer friendly" and emphasizes consumer choice and minimal disruption while changing from the current program to the MCO program

* Builds on Maryland's health care strengths -
a number of Medicaid recipients already participate in a Health Maintenance Organization (HMO) or have a primary care provider

* Provides a comprehensive, prevention and primary care-oriented system of health care -
Managed Care Organizations (MCOs) will stress health promotion/disease prevention and provide access to primary and speciality health care services MCOs will be required to meet performance standards and quality of care standards to meet the needs of all Medicaid recipients including special high-risk populations

* Holds MCOs accountable for quality health care - DHMH will monitor all MCOs closely to guarantee compliance to rigorous quality of care standards MCOs that do not meet these standards will be subject to sanctions including monetary penalties, and, potentially removal from the HealthChoice Programs

* MCOs will be paid on a fixed, per member per month scale (capitation) which will determine savings for the State

Overview of HealthChoice

The major features of HealthChoice are as follows:

* Eligible Medicaid recipients include low income women and children as well as the aged and disabled.

* Who is eligible for HealthChoice

All Medicaid/Medical Assistance recipients except: those in nursing homes, chronic care hospital facilities, mental hospitals or intermediate care facilities for the mentally retarded;

those eligible for short-term Medicaid benefits;

those individuals receiving Medicare;

those recipients enrolled in the Model Waiver program;

those receiving family planning services through the Family Planning Waiver Program; and

those receiving limited Medicaid benefits through the Maryland Kids Count Program.

* HealthChoice members will receive the current Medicaid benefits package and will be guaranteed eligibility for at least six months.

* The majority of Medicaid recipients will be able to remain with their current health care provider.

* HealthChoice will have twenty-one (21) days to choose a doctor and/or enroll in an MCO.

* Foster care children will be enrolled in an MCO within thirty (30) days.

* During the first year, enrollees may change MCO providers once for any reason.

- MCOs may not solicit or sign up members directly.
- Foundation Health Federal Services, Inc., the state's enrollment broker, will distribute the recipient enrollment packets. The packets will include:

  information on the MCOs in the recipient's area;

  provider lists and locations;

  a Health Risk Assessment for each family member; and

  MCO report cards based on patient satisfaction surveys.

- Health care services include inpatient care, outpatient care, primary care physician visits, pharmacy access and other ancillary services.
  Some MCos may offer dental services to adults as well as children.
- HealthChoice members will be able to self-refer for family planning services and access school-based health suites for care.
- HealthChoice MCOs will be responsible for primary mental health services.
  More intensive mental health will be handled by a separate mental health system administered by the DHMH Mental Hygiene Administration (MHA) through regional Core Services Agencies.
- Each HealthChoice MCO is required to have a consumer advisory board and provide an internal grievance procedure.
- DHMH will implement a statewide grievance/appeals process including an ombudsman service at the local health department and a toll-free hotline for recipient questions.
- MCOs may either be Health Maintenance Organizations (HMOs) or non-HMOs that meet state established quality-of-care criteria and financial solvency standards.
- Physicians, clinics, Medicaid HMOs and provider-bases organizations with a demonstrated history of successfully serving Medicaid recipients are guaranteed participation in HealthChoice.

HealthChoice and People with Special Health Care Needs

Health Choice

Information in this pamphlet does not apply to people in:

- Nursing homes
- Chronic hospitals
- Mental hospitals
- Intermediate care facilities for the mentally retarded (ICF-MR)
- The Model Waiver Program
- The Medicare program

These people are not in the HealthChoice program and will not be asked to choose an MCO.

HealthChoice and People with Special Health Care Needs

CONTENTS

Medicaid is changing

Medical Assistance will change, starting in June of 1997. The new program is called **HealthChoice**. Sometime between June and November 1997, you will get a notice in the mail. Then, you will need to sign up for an MCO and pick a doctor for your health care.

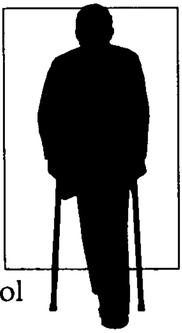
MCO stands for Managed Care Organization. **You will not lose any medical assistance benefits** when you join your MCO. In fact, your MCO will make sure your health care needs are met.

In a **HealthChoice MCO**, you and your doctor are partners in your care. Most of the time, your doctor will give you health care. If you need services from a specialist, your doctor will work with you to get them.

Health care services for people with special needs

MCOs give extra help to people who:

- have a physical disability
- have HIV/AIDS
- have a developmental disability
- have special mental health needs
- are pregnant or just had a baby
- are homeless
- need treatment to get off drugs and alcohol



HealthChoice helps children with special health care needs

MCOs offer extra services to children who:

- have special health care needs
- are in State supervised care, foster care or kinship care

Take these three steps to choose your MCO

1 Read your information packet

Between June and November of 1997, you will be asked to choose an MCO. You will get a packet in the mail and you will be asked to join an MCO. The packet has a list of all the MCOs in your area, names of doctors and an enrollment form. Call the number on the cover letter right away if you have questions.

2 Pick the MCO you want to join

You may have more than one doctor. Ask your doctors and specialist which MCO they belong to. Or find their names on the list you are given or call 1-800-977-7388.

If all of your doctors belong to one MCO, pick that MCO. If they do not belong to the same MCO, pick the one MCO that has the doctor you want to keep most. This may be your specialist.

3 Fill out the enrollment form

You can mail in your completed form or call **1-800-977-7388.** Call 1-800-977-7389 if you are hearing impaired. You may ask for a meeting in person. If you cannot get to a meeting because of a medical condition, ask for a home visit to sign up.

Make sure to answer the health information questions on your enrollment form. Your answers will help your MCO learn about your health needs. Your MCO can help you get medicine and services right away.

If you do not pick an MCO, the State will pick one for you.
Once you pick an MCO or are assigned one by the State, you can change to another MCO <u>one time</u> during the first year. People who move to a new county will be able to choose a new MCO near them at any time. If you need to change your MCO, call **1-800-977-7388**.

Your HealthChoice MCO and doctor will work with you.

√ Make an appointment with your MCO doctor or health care provider.

√ Tell your doctor about your health care history. Discuss the services that you got in the past. Your doctor can refer you to a specialist if needed.

Your doctor can help you continue to get Personal Care and Medical Day Care if you have these services now.

√ Get your questions answered by an MCO Special Needs Coordinator.

If you need a ride to your health visits because of a disability, call your local health department. The phone numbers are listed on the last page of this booklet.

Call 1-800-888-1965 if you are using mental health services now. Call if you think you need services.

If you need special services, your MCO must:

- Have doctors and other health care providers who are qualified to serve people with special medical needs.
- Give you a list of doctors who belong to the MCO.
- Assign a case manager and write a care plan if it is necessary. This person will see that your care plan is being carried out. They will also help you get referrals for other services.
- Get an assessment and a second opinion before you are transferred to a nursing home or institution for help with your physical disability. The MCO must ask for approval from the Department of Health and Mental Hygiene before you can be placed for more than a 30 day stay.

Your MCO invites people with special needs to serve on advisory boards in their community.

MCOs must follow rules of the Americans with Disabilities Act.

You have the right to:

An interpreter or other special communications help at no charge to you.

Get services at an accessible building.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Most children with special health care needs will be enrolled in MCOs.

▨ The MCO will:

- Refer the child to a health care provider who has experience in working with children with special health care needs.
- Offer services to children with developmental delays.
- Develop a complete care plan for each child.
- Provide case management services when needed to carry out the child's care plan.
- Provide medical equipment and assistive technology in a timely manner.

Children living in institutions and children in the Model Waiver and people with rare and expensive conditions will not enroll in an MCO. For information about rare and expensive conditions, call **1-800-565-8190**.

IF YOU HAVE A PHYSICAL DISABILITY

▨ Your MCO will:

- Offer medical equipment and assistive technology from a provider who has worked with people who have physical disabilities.
- Get an assessment and a second opinion before you are transferred to a nursing home or institution for help with your physical disability. The MCO must ask for approval from the Department of Health and Mental Hygiene <u>before</u> you can be placed for more than a 30 day stay.

IF YOU HAVE HIV/AIDS

MCO staff and all other people working with you must keep information about you confidential.

▨ Your MCO will:

- Offer case management services at the time you are told you have HIV/AIDS. You can request a case manager at any time.
- Talk to you about the full range of benefits you can get.
- Develop and update a complete care plan to meet your needs. **This plan can include:**

  √ Mental health services and treatment for drug and alcohol problems. You can get help for drug and alcohol problems within 24 hours of your request.

  √ Counseling.

  √ Information about financial aid, education, housing and social services.

- Refer you to places that can help you get into clinical trials.

Once each year, you can choose to have a medical and psychosocial assessment, called a diagnostic evaluation. Your MCO must pay for this service. Your MCO may also approve more diagnostic evaluations.

IF YOU HAVE A DEVELOPMENTAL DISABILITY

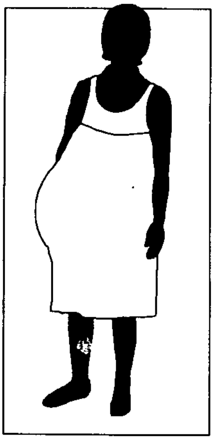
▨ Your MCO will:

- Make sure there will be no changes in the way you get services from the Developmental Disabilities Administration (DDA) and the DDA Waiver.
- Assign you a case manager who is trained and experienced in working with people who have developmental disabilities.

IF YOU HAVE SPECIAL MENTAL HEALTH NEEDS

People with special mental health needs will get services through a separate program. The program will help you get the mental health services you need. You can get help 24 hours a day, seven days a week. For more information, call 1- 800-888-1965.

IF YOU ARE PREGNANT OR JUST GAVE BIRTH



▨ Your MCO will:

- Give you a first prenatal visit within 10 days of request. Be sure to ask for an appointment as soon as you think you are pregnant.
- Help you find a doctor for your baby before your baby is born.
- Do a prenatal risk assessment and refer you to the Local Health Department if you need extra services.

- Refer you to a medical specialist if you have a high risk pregnancy.
- Give you a checkup after your baby is born. This visit will be scheduled within 10 days of your request.
- Help you make wise food choices.
- Offer ways to help you quit smoking.
- Refer you and your children under five years of age to the WIC (Women, Infants and Children's) Program for food and nutrition services.
- Give you an HIV test and counseling if you ask for it.
- Give you treatment for drug or alcohol problems within 24 hours of your request. This includes day treatment programs that allow you to bring your children.

IF YOU ARE HOMELESS

Homeless people have protection in the HealthChoice program. You will need to enroll in an MCO. The information about picking an MCO for your medical care may not reach you by mail. Call 1-800-977-7388 to enroll in an MCO.

▨ Your MCO will:

- Provide a case manager to coordinate your health care services.
- Design a treatment plan to meet your health needs.

IF YOU NEED HELP TO GET OFF DRUGS AND ALCOHOL

▨ Your MCO will:

- Talk to you about drugs and alcohol as part of your first health or prenatal visit.
- Tell you about programs to help you get off drugs and alcohol if you test positive for substance abuse.
- Offer treatment to help you get off drugs and alcohol (detox). This treatment may be either outpatient or inpatient depending on your medical needs.
- Offer you <u>outpatient</u> treatment to stay off drugs and alcohol.
- Offer the right kind of addiction programs for children under 21 and for adults eligible in TCA (Temporary Cash Assistance Program).

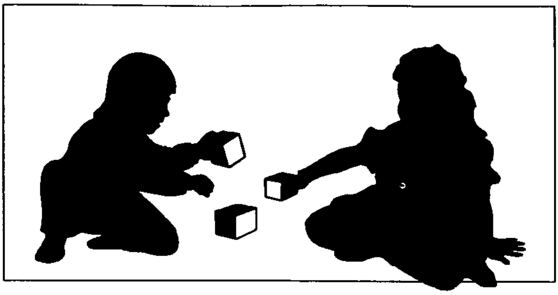
If you have HIV/AIDS and want help with a drug or alcohol problem:

- You will be able to get services to help you get off drugs and alcohol within 24 hours of your request.

If you are pregnant and want help with a drug or alcohol problem:

You will be given:

- Drug and alcohol abuse treatment within 24 hours of your request.
- Case management services.
- Intensive outpatient programs to address your needs. You can get treatment that allows your children to be with you.



SERVICES FOR CHILDREN IN STATE SUPERVISED CARE, FOSTER CARE OR KINSHIP CARE

Children in State supervised care will be enrolled in HealthChoice. A social worker from the Department of Social Services will work with foster parents and other care givers to choose the MCO. The choice will have to be made within 30 days of getting the notice.

▩ The MCO will:
  - Provide or arrange to provide all Medicaid covered services.
  - Appoint a coordinator to get services for these children and work with the Department of Social Services (DSS) foster care worker.
  - Provide medical care locally if a child is temporarily placed in another part of the State.

Children in State supervised care who have had a change in circumstances are allowed to change their MCO at any time. For example, children who move to an area outside their MCO service area will be given a new MCO near them.

Call your Local Health Departments for more information

Allegany County Health Department	(301) 777-5657
Anne Arundel County Health Department	(410) 222-4792
Baltimore City Health Department	(410) 396-4387
Baltimore County Health Department	(410) 887-2705
Calvert County Health Department	(410) 535-5400
Caroline County Health Department	(410) 479-0556
Carroll County Health Department	(410) 876-4972
Cecil County Health Department	(410) 996-5100
Charles County Health Department	(301) 934-9577
Dorchester County Health Department	(410) 228-3223
Frederick County Health Department	(301) 631-3104
Garrett County Health Department	(301) 334-8116
Harford County Health Department	(410) 879-2404
Howard County Health Department	(410) 313-6363
Kent County Health Department	(410) 778-7035
Montgomery County Health Department	(301) 217-1741
Prince George's County Health Department	(301) 817-3217
Queen Anne's County Health Department	(410) 758-0720
St. Mary's County Health Department	(301) 475-4330
Somerset County Health Department	(410) 651-5600
Talbot County Health Department	(410) 822-2292
Washington County Health Department	(301) 791-3232
Wicomico County Health Department	(410) 543-6980
Worchester County Health Department	(410) 632-1100

Ms. CHRISTENSEN. Thank you.

Go ahead, Peggy.

STATEMENT OF PEGGY L. BARTELS, DIRECTOR, DIVISION OF HEALTH, BUREAU OF HEALTH CARE FINANCING, WISCONSIN MEDICAID PROGRAM

Ms. BARTELS. Good morning. My name is Peggy Bartels, and I am the Director of the Bureau of Health Care Financing and am responsible for the administration of the Wisconsin Medicaid Program. Thank you for the opportunity to speak with you today.

My testimony has been provided to you as an attachment, a handout, if you'd like to follow along.

Wisconsin Medicaid is the State's largest health insurer. In fact, it is ten times larger than the single largest health insurer in the State. Our annual benefits budget is $2.4 billion, covering one of the broadest benefit packages in the Nation. Approximately 450,000 persons are eligible for Wisconsin Medicaid—almost 10 percent of the population.

We administer our Medicaid program in a highly efficient manner. Approximately three-quarters of our administrative resources are contracted to the private sector. Our administrative costs are just over 2 percent of our benefits costs, while the average health plan in Wisconsin has administrative costs ranging from 8 to 15 percent.

We have made a long-term commitment to managed care for Medicaid recipients. In general, we define "managed care" to mean capitated, risk-based contracts for comprehensive health care with licensed insurance companies that are HMOs. Wisconsin Medicaid started contracting with HMOs for low-income women and children in 1984, so we have a decade-and-a-half of experience.

Since then, we have started managed care programs for the elderly and disabled, which we are now evaluating and intend to expand. We have a strong HMO market in Wisconsin, and the benefits of Wisconsin Medicaid managed care are well-recognized. We have demonstrated significant savings while at the same time improving access and health care quality.

We currently administer the following specific managed care programs. Our largest HMO program is the one for low-income women and children, operating in 68 out of 72 countries—in fact, every county where there is an HMO. Nineteen HMOs provide comprehensive health care to 202,000 recipients. In addition, we administer numerous managed care demonstration projects for the elderly and disabled. These programs include our program for all-inclusive care for the elderly, the PACE projects, and our unique partnership program, an HMO program for disabled adults, and managed care programs for severely emotionally disturbed children. These programs are summarized in some detail in one of the attachments you have.

All of Wisconsin's managed care programs operate from the same basic principles: quality improvement activities must be multipronged—no one thing tells you what's going on. Medicaid managed care must be accountable to all interested parties. Managed care programs must be targeted to the enrolled population, and a broad public-private partnership is necessary to succeed.

These principles apply to managed care for all enrolled populations, including children and adults with special health care needs. We define persons with special health care needs to include frail elderly and disabled children and adults. We define disabled children and adults to include persons with developmental delays or disabilities, alcohol or other drug abuse problems, physical disabilities, or mental illness. Persons in all of these groups are enrolled in managed care in Wisconsin. Many of the children in our largest HMO program for low-income families have special health care needs.

Wisconsin's managed care principles allow and in fact require our targeted programs to be flexible and responsive to different recipient groups. However, the fundamental strategies needed to support these principles are the same regardless of the population served.

It is important to note that the States need flexibility to implement these principles. I will describe for you what has worked in Wisconsin, but must emphasize that States are different, and one size does not fit all.

We believe that the great secret of Medicaid managed care is that State Medicaid programs with their attention to populations most at risk are improving managed care for everyone. In order to meet our unique requirements and standards, we have found that our commercial HMOs have to change the way they do business, and when they change, they do it for everyone, not just for Medicaid recipients.

At the forefront of Wisconsin's managed care infrastructure is this broad public-private partnership I referred to. We must work together to implement our multi-pronged quality improvement process. The goals of our QI process are simple but broader than many commercial managed care plans.

First, we strive to ensure that Medicaid managed care enrollees achieve the highest possible outcomes, whether the enrollee is a 2-year-old needing to be fully immunized or an 80-year-old needing assistance with appropriate medication administration. We define desired health outcomes differently for different populations. We strive to define outcomes that are both objectively and clinically acceptable and subjectively important to the consumers. We are learning that there is a lot of work to be done to define outcomes that are acceptable to the elderly and disabled. Traditional quality measures such as those defined in HEDIS are just a starting point.

Second, we strive to make sure our managed care enrollees' access the care they need, whether that means assuring transportation to clinic appointments or locating translators. Again, we define opportunities for improved access differently for targeted populations. We are learning, for example, that elderly persons are much more likely to access health care if they feel they have a comfortable personal relationship with their health care provider. This is not a common goal in commercial managed care plans.

Finally, we are committed to ensuring enrollees' maximum choice of managed care plans and health care providers within those plans. When we cannot guarantee reasonable choice, we do not enroll.

We implement these QI goals through a variety of strategies. Most importantly, we have established basic contract requirements, some of which apply to all managed care enrollees and some of which are unique. The contract requirements are routinely and rigorously monitored.

Examples of contract requirements are ensuring around-the-clock easy access to appropriate care; assuring the location of health care providers within 20 miles of consumers' residences—we believe this is the strictest requirements in the Nation; requiring that managed care organizations offer a comprehensive range of services equivalent to Medicaid fee-for-service; assuring culturally responsive health care providers education and communication; requiring formal and informal complaint and grievance processes, and requiring managed care organizations to maintain a comprehensive internal QI system. Almost all State Medicaid managed care programs include such requirements.

Examples of contract requirements that are unique to Wisconsin include the following. We use an independent enrollment contractor to assure that Medicaid recipients enrolling in HMOs are fully informed about how to choose an HMO that best meet their needs. Our enrollment contractor also assists recipients with formal and informal complaints and grievances.

Our contract requires each HMO to hire at least one full-time Medicaid advocate to help enrollees navigate the managed care system. We contract with two ombudsmen to help Medicare enrollees with more systemic complaints and grievances. We enroll voluntary HMO participation for children who qualify for the Federal birth to 3 program, a program targeted for children with special health care needs. By the way, most parents and caregivers opt to give their children the HMO program.

Specific targeted contract requirements for the elderly and disabled include the following. Each managed care organization must have a board of directors including Medicaid consumer representatives. Our plans must have working memoranda of understanding with affected counties, because in Wisconsin, many behavioral health and supportive home care services are county-based. Required quality studies must reflect some subjects of importance to consumers.

All of our special managed care programs are undergoing extensive quality evaluations by outside evaluators. This has been the Wisconsin way. We start slowly, evaluate and improve, and then expand to larger numbers.

Every year, Wisconsin produces the HMO fee-for-service comparison report, an extensive document—I brought a copy so you can see how big it is. This report is based on a combination of survey and encounter data submitted and processed by HMOs. The report is always made public, with the results discussed in many public forums. Areas needing improvement may be further studied by work groups and audited. We will be producing similar reports for our other programs also. We have a strong audit and utilization reporting components. We regularly conduct comprehensive medical chart reviews. We cover twice as many chart reviews from managed care enrollees as for fee-for-service enrollees. All of these strategies can be adapted to special Medicaid populations including persons with special health care needs.

Finally, a word about our public-private partnership. We have this in Wisconsin because we made it happen. We require our HMOs to attend our public meetings and work together with community-based organizations, counties and tribes. We foster informed and proactive advocacy through HMO advocates, ombudsman, numerous public work groups and meetings. We report on our results, both good and bad, and work together on program improvement. We keep policymakers informed through publications such as "Forward" our monthly managed care newsletter. We highlight best practices at public meetings.

In general, we use our contract requirements and the resources of the State to foster information-sharing and trust-building. We have found this approach to be extremely effective in the current anti-managed care environment. This is why 19 of the 25 licensed HMOs in the State contract with us and why advocates in counties are pushing us to expand managed care to the elderly and disabled and why policymakers in Wisconsin look to the Medicaid contract as the standard for commercial managed care.

The results of Medicaid managed care in Wisconsin have been significant savings and better health care for recipients. We estimate managed care has saved Wisconsin taxpayers over $100 million from 1990 to the present, and we have demonstrated improved access and quality through reports such as the one I indicated.

What lessons have we learned about the critical capacities of States to operate successful managed care programs, especially for persons with special health care needs? States and managed care plans need enough time to plan, sign contracts, enroll recipients, and develop necessary relationships to provide the quality managed care programs States now expect. They need to be able to develop and enforce strict contract standards. To develop effective contracts, State Medicaid programs must shift to a new buyer mindset. We see ourselves as purchasing for outcomes rather than paying for services or regulating for potential violations.

But strong contract requirements alone will not ensure high-quality managed care programs. States also need the ability to maximize significant resources either through redeployment, contract staff, or in rare instances in these times, new staff, in order to create the infrastructure needed to support effective contract enforcement.

In Wisconsin, we have a small managed care section of 21 full-time employees. Two of these employees are borrowed from other divisions in our department. About 10 to 15 staff from other areas of the Medicaid program are redeployed to help us with certain activities like audits. We also use a lot of private contracted resources. We have an enrollment contract of $1.7 million per year, a contract for external peer review, $1.4 million per year, special staff from our fiscal agent to assist us with day-to-day operations, two ombudsmen, six contract monitors, four systems business analysts to help HMOs with their utilization reporting. We also spend about half a million dollars a year on contract actuarial services.

States need significant resources to assist managed care organization used to working with commercial populations to work with

Medicaid recipients. Medicaid managed care is very different from commercial managed care. To be successful, managed care organizations need to recognize these differences, and States need to help them learn how to adapt their product lines to serve Medicaid recipients. Medicaid offers more benefits than most commercial health plans ever dreamed of. It is subject to greater public oversight, has more Federal requirements than commercial insurance. Medicaid recipients are poor, generally less educated and have chronic health problems and access problems that the commercial population may not have.

We believe that our Medicaid contract requirements, with their emphasis on special health care needs of low-income people have resulted in significant changes in Wisconsin in commercial managed care.

Developing.the kind of broad infrastructure I have described takes time and money. Many State Medicaid programs, including Wisconsin's, have invested both for some time now. Medicaid has become the national laboratory to refine and improve managed care. I am confident that States can use their resources and experience to improve health care for persons with special health care needs while continuing to slow the rate of expenditure growth.

[The prepared statement of Ms. Bartels follows:]

Tommy G. Thompson
Governor

Joe Leean
Secretary

State of Wisconsin
Department of Health and Family Services

DIVISION OF HEALTH

1 WEST WILSON STREET
P. O. BOX 309
MADISON WI 53701-0309

TESTIMONY OF

PEGGY L. BARTELS

DIRECTOR
BUREAU OF HEALTH CARE FINANCING
WISCONSIN MEDICAID

BEFORE THE U.S. SENATE SPECIAL
COMMITTEE ON AGING

JULY 22, 1997

My name is Peggy Bartels. I am the Director of the Bureau of Health Care Financing and am responsible for the administration of the Wisconsin Medicaid program. Thank you for the opportunity to speak with you today.

Wisconsin Medicaid is the State's largest health insurer. Our annual benefits budget is $2.4 billion, covering one of the broadest benefit packages in the nation. Approximately 450,000 persons are eligible for Wisconsin Medicaid -- almost 10% of the State's population. The Medicaid population in Wisconsin is typical of other state Medicaid programs. Approximately 66% of Medicaid recipients are low-income women and children, and 34% are elderly and disabled. The cost of these populations is proportionally opposite the number of eligibles. Low-income women and children account for 27% of Medicaid costs, while the elderly and disabled account for 73% of Medicaid costs.

Wisconsin administers Medicaid in a highly efficient manner. Approximately three quarters of our administrative resources are contracted to the private sector. Wisconsin's administrative costs are just over 2% of benefit costs, while the average health plan in Wisconsin has administrative costs that range between 8 - 15% of benefits paid.

Wisconsin has made a long-term commitment to managed care for Medicaid recipients. In general, we define "managed care" to mean capitated, risk-based contracts for comprehensive health care with licensed insurance companies that are HMOs.

Wisconsin Medicaid started contracting with HMOs for low-income women and children in 1984. Since then, we have started small managed care programs for the elderly and disabled, which we are now evaluating and intend to expand. We have a strong HMO market in Wisconsin, and the benefits of Wisconsin Medicaid managed care are well recognized. We have demonstrated significant savings, while at the same time improving access and health care quality.

We currently administer the following specific managed care programs:

- Our HMO program for low-income women and children is our largest managed care program, operating in 68 of 72 counties. Nineteen HMOs provide comprehensive health care services to 202,000 recipients.

In addition, we administer numerous managed care demonstration projects for the elderly and disabled. These include our Program for All-Inclusive Care for the Elderly (PACE) and Partnership programs, an HMO program for disabled adults, and managed care programs for severely emotionally disturbed (SED) children.

- The PACE/Partnership programs are targeted to the elderly and physically disabled. In 1989, Wisconsin was one of the first five states to replicate the PACE model for the elderly. In 1995, Wisconsin created a unique new model for the elderly and persons with disabilities called the Wisconsin Partnership Program. Both programs provide comprehensive health care, but with different delivery models, quality improvement systems, and provider contracting arrangements. Today, Wisconsin operates the PACE model to serve the elderly in Milwaukee and Madison and the Partnership model to assist the elderly and persons with physical disabilities in Dane County and in rural Eau Claire, Dunn, and Chippewa counties. The current enrollment in Wisconsin's PACE/Partnership program in all sites is 563 recipients.

- We also are just completing a research and demonstration grant through a risk-based capitated HMO for disabled adults in Milwaukee County. This model is unique in the country in that it represents a partnership between a medical HMO (Humana/WHO) and a community-based organization (the Milwaukee Center for Independence). The hybrid organization is called I-CARE (2,714 enrollees).

- Finally, we operate a carve-out behavioral health managed care program for children with severe emotional needs in two urban counties, Dane and Milwaukee (344 enrollees). Both programs are fully risk-based.

All of Wisconsin's managed care programs operate from the same basic principles. These are:

- quality improvement activities must be multi-pronged;
- Medicaid managed care must be accountable to all interested parties;
- managed care programs must be targeted to the enrolled populations; and finally,
- a broad public/private partnership is necessary to succeed.

These principles apply to managed care for all enrolled populations, including children and adults with special health care needs. We define persons with special health care needs to include the frail elderly and disabled children and adults. Disabled children and adults are persons with developmental delays or disabilities, alcohol or other drug abuse problems, physical disabilities, or mental illness. Persons in all these groups are enrolled in managed care in Wisconsin. Many of the children in our largest HMO program for low-income families have special health care needs.

Wisconsin's managed care principles allow, and in fact require, our targeted programs to be flexible and responsive to different recipient groups. However, the fundamental strategies needed to support these principles are the same regardless of the population served.

It is important to note that states need flexibility to implement these principles. I will describe what has worked in Wisconsin, but must emphasize that states are different and "one size does not necessarily fit all."

We believe the great secret of Medicaid managed care is that state Medicaid programs, with their attention to populations most at risk, are improving managed care for everyone. In order to ~~meet our~~ unique requirements and standards, we have found that our commercial HMOs have changed the way they do business -- and when they change, they do it for all enrollees, not just for Medicaid.

At the forefront of Wisconsin's managed care infrastructure is a broad public/private partnership. We all must work together to implement our multi-prolonged quality improvement (QI) process. The goals of our QI process are simple, but broader than many commercial managed care programs.

First, we strive to ensure that Medicaid managed care enrollees achieve the highest possible health outcomes, whether the enrollee is a 2-year-old needing to be fully immunized, or an 80-year-old needing assistance with appropriate medication administration. We define desired health care outcomes differently, for different populations. We strive to define outcomes that are both objectively and clinically acceptable and subjectively important to consumers. We are learning that there is a lot of work to be done to define outcomes that are acceptable to the elderly and disabled. Traditional quality measures, such as those defined in HEDIS, for example, are just a starting point.

Secondly, we strive to make sure our managed care enrollees access the care they need, whether that means assuring transportation to clinic appointments or locating translators for non-English speaking enrollees. Again, we define opportunities for improved access differently for targeted populations. For example, we are learning that elderly persons are more likely to access health care if they feel they have a comfortable personal relationship with their health care provider. This is not a common goal in commercial managed care.

Finally, we are committed to ensuring enrollees maximum choice of managed care plans and health care providers within those plans. Whenever we cannot guarantee reasonable choice -- we do not enroll.

We implement these QI goals through a variety of strategies. Most importantly, we have established basic contract requirements, some of which apply to all Medicaid managed care enrollees and others which are unique to each population. The contract requirements are routinely and rigorously monitored for all programs.

Examples of these contract requirements are: assuring round-the-clock easy access to appropriate care; assuring the location of health care providers within 20 miles of consumers' residences; requiring that managed care organizations offer a comprehensive range of services equivalent to Medicaid fee-for-service; assuring culturally responsive health care providers, education and communication; requiring formal and informal complaint and grievance processes; and requiring managed care organizations to maintain a comprehensive internal QI system. Almost all state Medicaid managed care programs include such requirements.

Examples of contract requirements that are unique to Wisconsin's statewide managed care program for low-income women and children that could be adapted for mandatory programs for the elderly and disabled include the following features:

1) We use an independent enrollment contractor to assure that Medicaid recipients enrolling in HMOs are fully informed about how to chose an HMO that best meets the health care needs of their family. The enrollment contractor helps Wisconsin avoid excessive and inappropriate marketing to consumers by HMOs.

2) Our contract requires each HMO to hire at least one full-time Medicaid advocate to help enrollees navigate the managed care system and learn how to use their HMO effectively.

3) We contract with two ombudsmen to help managed care enrollees with more systemic complaints and grievances about managed care.

4) We allow voluntary HMO participation for children who qualify for the federal "Birth-to-Three" program – a program targeted for children with special health care needs. Most parents and caregivers opt to keep their children in the HMO program.

Specific, targeted contract requirements for the elderly and disabled also include the following: each managed care organization must have a Board of Directors including Medicaid consumer representatives; our plans must have working Memoranda of Understanding with affected counties (in Wisconsin, many behavioral health and supportive home care services are county based); and required quality studies must reflect some subjects of importance to consumers. All of our special managed care programs are undergoing extensive quality evaluations by outside evaluators. This has been the Wisconsin way: we start slowly, evaluate and improve, then expand to larger numbers of covered persons.

Another critical aspect of our multi-pronged QI approach is public accountability. We use an extensive network of community-based forums as vehicles for public input on all aspects of managed care. Examples of these meetings include: a Statewide Advisory Group, quarterly meetings with HMO technical staff, monthly meetings with HMO contract administrators, quarterly regional forums and workgroups (statewide or regional) to address specific areas of concerns (e.g., behavioral health). We foster and encourage proactive advocacy and community involvement as part of our public/private partnership.

Every year Wisconsin produces an HMO/Fee-For-Service Comparison Report for the low-income women and children managed care enrollees. This report is based on a combination of survey and encounter data submitted and processed by HMOs. The report is always made public with the results discussed in public forums. Areas needing improvement may be further studied by workgroups and audited. We will be producing similar reports for our other programs also.

Wisconsin has a strong audit and utilization reporting component to its multi-pronged QI approach. We target specific areas of concern, such as behavioral health and dental services.

We also regularly conduct comprehensive medical chart reviews of both fee-for-service and managed care recipients through an independent peer review organization. We review twice as many charts for Medicaid managed care enrollees as for those on Medicaid fee-for-service.

All of these strategies – contract requirements, enrollment contractors, advocates, public forums, public reporting of data, audits and chart reviews – can be adapted to all special Medicaid populations, including persons with special health care needs.

Finally, we believe that high quality managed care programs for Medicaid populations require a strong public/private partnership. We have this in Wisconsin because we have made it happen. Our contract requires HMOs to attend our public meetings and work together with community-based organizations and counties. We foster informed and proactive advocacy through HMO advocates, state-sponsored ombudsmen, and numerous public workgroups and meetings. We report on our results -- good and bad -- and work together on program improvements. We keep top policy makers informed through publications such as Forward, our monthly managed care newsletter. We highlight "best practices" at our public meetings. In general, we use our contract requirements and the resources of the State Medicaid program to foster information-sharing and trust-building.

We have found this approach to be very effective in the current "anti-managed care" environment. This is why 19 of the 25 HMOs licensed in Wisconsin contract with Medicaid, why advocates and counties are pushing us to expand managed care to the elderly and disabled, and why policy makers in Wisconsin look to the Medicaid contract as the standard for commercial managed care.

The results of Medicaid managed care in Wisconsin have been significant savings and better health care for recipients. We estimate managed care has saved Wisconsin taxpayers over $100 million, from 1990 to the present time, compared to traditional Medicaid fee-for-service. In 1996, we saved $16 million over comparable fee-for-service expenditures.

Access to care has improved for Medicaid recipients enrolled in our mandatory HMO program for low-income women and children as measured by our 1995 HMO/Fee-For-Service Comparison Report. For example, in 1995, HMO recipients visited Medicaid health care providers more often than their fee-for-services counterparts and visited emergency rooms half as often as their fee-for-service counterparts. Children in Medicaid HMOs receive more well-child visits, more immunizations and more specialty care. Women in HMOs were more likely to receive at least one Pap test and had fewer Cesarean sections.

What lessons have we learned about the critical capacities of states to operate successful managed care programs, especially for persons with special health care needs?

States and managed care plans need enough time to plan, sign contracts, enroll recipients, and develop necessary relationships to provide the quality managed care programs states now expect. They need to be able to develop -- and enforce -- strict contract performance standards. To develop effective contracts, state Medicaid programs must shift to a new "buyer" mindset. We see ourselves purchasing for outcomes, rather than paying for services or regulating for potential violations.

But strong contract requirements alone will not ensure high quality managed care programs. States also need the ability to maximize significant resources, either through redeployment, contract staff, or in rare instances in these times, new staff, in order to create the infrastructure needed to support effective contract enforcement. In Wisconsin, we have a small managed care section of 21 full-time employees. Two of these employees are "borrowed" from other divisions in our Department. About 10 - 15 staff from other areas in the Medicaid program are "redeployed" to help us on certain activities, like audits. We also use a lot of private, contracted resources to help us oversee managed care. We have an enrollment contract of $1.7 million per year, a contract with an external peer review organization of $1.4 million per year, special staff from our fiscal agent to assist us with day-to-day operations of managed care – two Ombudsmen, six Contract Monitors, and four systems/business analysts to help HMOs with their utilization reporting. We also spend about $0.5 million per year on contracted actuarial services.

States need significant resources to assist managed care organizations used to working with a commercial population to work with Medicaid recipients. Medicaid managed care is very different from commercial managed care. To be successful, managed care organizations need to recognize these differences and states need to help them learn how to adapt their product lines to serve Medicaid recipients. Medicaid offers more benefits, is subject to greater public oversight, and has more federal requirements to meet than commercial insurance. Medicaid recipients are poor, generally less educated, and have more chronic health problems than the commercial population. Medicaid recipients have more barriers to accessing health care, including the lack of transportation, inability to speak English and cultural differences. We believe that our Medicaid contract requirements, with their emphasis on the special health care needs of low-income people, have resulted in significant changes in the commercial managed care environment.

Developing the kind of broad infrastructure I have described – strong contract requirements; credible vehicles for public accountability; programs tailored to consumers needs and preferences; adequate access, choice and opportunity for consumer input; and strong audit and enforcement capacities – takes time and money. Many state Medicaid programs, including Wisconsin's, have invested both for some time now.

Medicaid has become the national laboratory to refine and improve managed care. I am confident that states can use their resources and experience to improve health care for persons with special health care needs, while continuing to slow the rate of Medicaid expenditure growth.

WISCONSIN DEPARTMENT OF HEALTH AND FAMILY SERVICES

Joe Leean, Secretary

DIVISION OF HEALTH

J. Jean Rogers, Administrator

DIVISION OF HEALTH, BUREAU OF HEALTH CARE FINANCING

Peggy L. Bartels, Director

WISCONSIN MEDICAID

FOR MORE INFORMATION, CONTACT

Angela Dombrowicki, Managed Care Section Chief

BUREAU OF HEALTH CARE FINANCING

One West Wilson Street
P.O. Box 309
Madison, WI 53701-0309
Telephone: 608-266-1935
FAX: 608-266-1096

INTERNET ADDRESSES:

Ms. Bartels: barteple@dhfs.state.wi.us
Ms. Dombrowicki: dombra@dhfs.state.wi.us

WISCONSIN MEDICAID

HMO / *Fee-for-Service*

COMPARISON REPORT: 1995

HMOs reported higher rates of preventive services than fee-for-service in several important areas. Medicaid managed care enrollees were reportedly more likely to receive "well-child" exams (HealthChecks), MMR vaccines, and Pap tests, for example, than fee-for-service recipients. In general, access to care was equal to, or better than, fee-for-service. HMO enrollees visited primary care providers more and emergency rooms less often than fee-for-service recipients. In the area of mental health, HMOs as a whole reported lower rates of persons receiving services. But, of those receiving mental health care, the average number of services per recipient was nearly the same as fee-for-service.

BACKGROUND

Wisconsin was one of the first states to contract with health maintenance organizations (HMOs) to provide health care services to Medicaid recipients. Rapidly rising costs, fragmented care delivery, and concerns about access to care and quality prompted a search for alternatives to the fee-for-service Medicaid system. Since the inception of the Wisconsin Medicaid HMO program in 1984, many other states have followed Wisconsin's lead and have implemented Medicaid managed care programs.

Because of the success of the first Medicaid HMO programs in Milwaukee, Dane, and Eau Claire counties, managed care for the Aid to Families with Dependent Children (AFDC)/Healthy Start population was expanded. In 1995, 11 HMOs served almost 150,000 Medicaid recipients in five Wisconsin counties. By the end of 1997, approximately 200,000 Wisconsin Medicaid recipients will receive their health care through 19 HMOs.

AFDC and Healthy Start Medicaid recipients are, for the most part, children and women in their childbearing years. More than two-thirds are under 20 years of age. Almost 90 percent of adult recipients are women, and less than one percent are over 50 years of age. The health care challenge for this young and predominantly female population is to provide important preventive services and to assure access to and continuity of care.

The *Wisconsin Medicaid HMO/Fee-for-Service Comparison Report: 1995* is only one of several ways the Wisconsin Medicaid Program reports on and monitors care provided to Medicaid recipients in both Medicaid-contracted HMOs and fee-for-service health care delivery areas. This report is produced annually. Data for the report reflect care provided to the Medicaid AFDC and Healthy Start populations only and are derived from two data sources: data reported by individual Medicaid-contracted HMOs and claims submitted to the Wisconsin Medicaid fiscal agent, EDS. The report compares reported health care utilization and occurrence data among HMOs, among HMO counties, and between HMO and fee-for-service. The report presents 59 indicators. Several are of particular relevance and importance to the AFDC/Healthy Start population.

SELECTED INDICATORS

Access to Care

- *Children and adolescents in HMOs had slightly higher rates of health care visits for all reasons (62%) than in fee-for-service (57%).*

Percent of recipients (ages 0-20) having at least one health care visit in 1995

- *HMOs reported that three times as many enrollees were seen by primary care providers (59%) than in fee-for-service (19%).* Primary Care Providers (PCPs) are typically the cornerstone of care provided through HMOs. As the coordinator of care, the PCP provides a "medical home" for managed care recipients.

Percent of recipients seen by a primary care provider in 1995

- *HMOs reported half as many emergency room visits as fee-for-service (0.6 versus 1.2 visits per eligible per year).* Inappropriate emergency room use is often associated with poor continuity of care and unnecessary costs. Especially among the poor, emergency rooms may provide the only medical services received. Strategies such as assuring that every enrollee has his or her own primary care provider, that a caregiver is "on call" 24 hours a day, and that patients contact their own doctors first in non life-threatening situations have helped reduce inappropriate emergency room use.

Average number of emergency room visits per eligible year in 1995

Children's Health

- *"Well-baby/child" checks, called HealthCheck Screens, were reported much more frequently in HMOs than in fee-for-service for children from the age of birth through five.* Fifty-one percent of children in this age group received a HealthCheck from an HMO provider as opposed to only 32 percent of those in fee-for-service. Of the five HMO counties, Milwaukee had the highest rate of screens. HealthChecks are performed to monitor a child's development in a variety of areas and to provide education to parents. HealthChecks are often timed to coincide with immunizations.

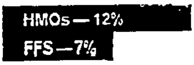
Percent of children (ages 0-5) who received at least one HealthCheck visit in 1995

- ***Children ages one through five enrolled in HMOs were twice as likely to receive the Measles, Mumps, and Rubella (MMR) vaccine as children enrolled in fee-for-service.*** In the aggregate, HMOs reported that they administered the MMR vaccine to 20 percent compared to only ten percent of children in this age range receiving Medicaid services through the fee-for-service system. In recent years, many Wisconsin children contracted measles because they had not been immunized. Children should receive the MMR vaccine first between 12 and 15 months of age and again between age four and six. Six cases of measles were reported in Wisconsin in 1995.

Percent of children (ages 1-5) who were given the MMR vaccine in 1995

- ***HMOs reported performing lead tests on children from birth to 20 years of age almost twice as often (12%) as fee-for-service (7%). Milwaukee HMOs reported the highest rates of lead screens (14%).*** High lead levels can result in serious developmental problems, especially in the very young.

Percent of children (ages 0-20) who had at least one blood lead test in 1995



Women's Health

- ***HMOs reported much higher Pap test rates (34%) in women over 20 years of age than did fee-for-service (20%).*** Due in great part to increased Pap test rates, fewer than three women in every 100,000 die each year from cervical cancer. Women should have a Pap test every one to three years, depending on their risk.

Percent of women (ages 21 and above) who had at least one Pap test in 1995

- ***HMOs reported fewer Cesarean section deliveries (12%) as compared to fee-for-service (17%).*** Cesarean section deliveries have been associated with higher rates of complication and death when compared to vaginal deliveries.

Percent of deliveries that were Cesarean sections in 1995

Mental Health

- *HMOs reported fewer numbers of persons who received at least one mental health visit (3%) than did fee-for-service (5%). However, of those persons who did receive at least one mental health visit, the number of services received in 1995 was similar between HMOs (5.3) and fee-for-service (5.8).* Mental illness affects a large number of people, especially adolescents and adults. Differences between fee-for-service and HMOs relating to coding, prior authorization for mental health services, and different styles of service delivery may account for higher numbers of reported encounters in fee-for-service. For example, mental illnesses, such as depression, are often treated by primary care physicians. Mental health screening visits are not reported here. Based on these data, little can be said about quality and outcomes for persons with mental illnesses. Assuring that Medicaid recipients have access to quality mental health services is important. For this reason, several activities related to mental health have been initiated by the state: Medicaid studies involving audits and chart reviews have been conducted, a "Mental Health/AODA Workgroup" was recently reconvened, and special program to train primary care providers to aggressively screen for common mental illnesses and substance abuse will begin in 1997.

Percent of recipients who had at least one mental health/AODA visit in 1995

Average number of visits among those receiving one or more mental health/AODA services in 1995

Chronic Conditions

- *In children and adolescents, the diagnosis of asthma is more common among HMO enrollees (4%) than in fee-for-service (2%), with Milwaukee HMO recipients reporting the highest rate of asthma diagnoses (5%). However, the rate of hospitalizations for asthma was four times as high among children and adolescents in managed care (0.4% versus 0.1%).* Asthma is a chronic and sometimes life-threatening disease. It is the most common chronic disease in young people. African Americans and people who live in cities are affected more often than others. Many asthma hospitalizations may be avoidable. Without having other information, such as severity for example, conclusions about quality of care are not possible. Since 1995, several HMOs have initiated asthma outreach and intervention programs.

Percent of recipients with a diagnosis of asthma in 1995

Percent of recipients hospitalized for asthma in 1995

QUALITY IMPROVEMENT

The *Wisconsin Medicaid HMO/Fee-for-Service Comparison Report: 1995* is only one of several ways Wisconsin monitors quality and access for the Medicaid population. Contract monitoring, audits, and chart reviews are examples of other important quality improvement activities. In 1997, a consumer satisfaction survey will be conducted in Milwaukee.

As managed care coverage expands in the state, Wisconsin's Department of Health and Family Services will continue to work with managed care organizations in a proactive partnership to achieve the highest possible health outcomes for Medicaid managed care recipients and to report to the public on quality-related issues in a useful and "user-friendly" way.

Wisconsin Medicaid Managed Care Programs Overview

Program Characteristics	AFDC/HS Medicaid HMO	Primary Provider Program (PPP)	Independent Care (I-Care)	Program for All Inclusive Care for the Elderly (PACE)	WI Partnership Program	Children Come First (CCF)	WrapAround Milwaukee (WAM)	High Cost Case Management (HCCM)
tate of nplementation	1977 (expansions in 1984 and 1995 and statewide expansion in 1996)	December 1, 1994 (Program is expected to terminate on May 29, 1997.)	July 1, 1994	1) Community Care Organizations, Inc. in November 1989 in Milwaukee. 2) Elder Care of Dane Co., Inc. in January 1995.	1) Elder Care of Dane Co., Inc. in January 1996. 2) Community Care Organizations, Inc. in April 1996. 3) ACCESS to Independence in June 1996. (Center for Independent Living for Western Wisconsin in May 1997.)	April 1993	March 1997	May 1997
rogram sites	All counties, excluding Door, Florence, Kewaunee, and Marinette counties.	Milwaukee County	Milwaukee County	One program in Milwaukee and one in Dane County.	Dane, Milwaukee, and Eau Claire Counties	Dane County	Milwaukee County	Statewide.
rogram description nd approach to anaging care	Recipients are assigned to and receive all care and services through a contracted HMO. HMO is responsible for providing directly or contracting for covered services to the enrolled population.	Recipients are linked to a primary care provider who coordinates the delivery of health care services.	Care coordinators and a network of providers coordinate medical and social services for SSI disabled Medicaid recipients.	Provide frail elderly individuals the support needed to avoid nursing home placement through provision of comprehensive medical and psychosocial services by a multi-disciplinary team.	Demonstration project that provides home and community care, comprehensive/ integrated services to the frail elderly and persons with physical disabilities.	Multi-agency, community-based system of mental health services for children with severe emotional disturbances (SED).	Same as CCF	Better manage and coordinate care needed by recipients with certain high cost diagnoses.
rogram goals	Improve quality of care through better access to and continuity of medical care. Reduce costs through better management and reducing inappropriate care.	Improve access to primary care services by creating a "medical home" for the recipient. Reduce costs by reducing duplication of services and unnecessary care.	Goal is to integrate medical and social services and improve quality, access, and coordination of medical services. Reallocate resources for disabled recipients.	Allow elderly to remain in community-based resources and their homes by providing community-based services. Contain acute and long term care costs.	Two models, one for elderly and one for physically disabled. Integrate acute and long term care service delivery, and maximize ability of enrollees to remain in their own homes.	Keep children with SED out of institutions. Reallocates resources previously used for institutionalization to community based services for children with SED.	Same as CCF	Improve quality of care, and reduce costs through better management and elimination of inappropriate services for recipients with designated high cost diagnoses.

Program Characteristics	AFDC/HS Medicaid HMO	Primary Provider Program (PPP)	Independent Care (I-Care)	Program for All Inclusive Care for the Elderly (PACE)	WI Partnership Program	Children Come First (CCF)	WrapAround Milwaukee (WAM)	High Cost Case Management (HCCM)
uthority and funding ource	State Medicaid agency and Federal government. (1915(b) waiver).	State Medicaid agency and Federal government (1915(b) waiver).	Three year research and demonstration grant from HCFA.	OBRA of 1986 gave federal authority for On Lok to replicate the Pace model. Medicare and Medicaid pay capitated rate to PACE sites.	Grant from RWJ Foundation administered by State Medicaid agency. Medicaid revenues.	RWJ Foundation grant initially. Currently joint funded by DHFS and Dane County Department of Human Services.	Initially a 5 year CMHS grant. Now continued through joint funding by DHFS and Milwaukee County DHS.	State Medicaid agency.
ype of enrollment oluntary or andatory)	Voluntary for eligible recipients in zip codes with one participating HMO and mandatory for eligible recipients in zip codes with two or more participating HMOs. Recipient may obtain an exemption if criteria are met.	Initially mandatory for eligible recipients. Voluntary as of November 1, 1996.	Voluntary. Recipients are selected at random to receive informing packet.	Voluntary	Voluntary	Voluntary	Voluntary	Voluntary
igible population	AFDC and Healthy Start recipients residing in zip codes with one or more participating HMOs. Dual eligibles are excluded. Exemption criteria exists. Healthy Start is a program for pregnant women and children whose family income is under 185% of the poverty level.	SSI disabled Medicaid recipients residing in Milwaukee County. Dual eligibles and persons enrolled in managed care, in foster care, or assigned to the recipient lock-in program are excluded.	SSI disabled recipients who are dually eligible for Medicare and Medicaid and reside in Milwaukee County. Recipients must be Med Stat Code 21 and must not be institutionalized. Cannot be enrolled in other managed care or waiver programs (e.g., CIP, COP, CSP).	Frail elderly, nursing home eligible enrollees who are dually eligible for Medicare and Medicaid. Potential eligibles must meet both the income and nursing home level-of-care eligibility criteria for Medicaid.	Frail elderly and physically disabled, dually-eligible. Recipient must meet level of care criteria for nursing home admission or must have substantial illness or disability.	Child or adolescent Medicaid recipient and client of Dane Co. Human Services Department. Must have severe emotional disturbance as defined in HSS 107.32, Wis. Admin. Code, and be at imminent risk of institutional admission to a psychiatric hospital, placement in a child caring institution, or juvenile correction facility.	Child or adolescent Medicaid recipient and client of Milwaukee Co. Human Services Department. Must have severe emotional disturbance as defined in HSS 107.32, Wis. Admin. Code, and be at imminent risk of institutional admission to a psychiatric hospital, placement in a child caring institution, or juvenile correction facility.	Non-institutionalized (or pending discharge) Medicaid recipients with anticipated expenditures >$25,000 per year. Recipient must have primary diagnosis in one of the targeted diagnosis categories. (Excludes mental health/AODA diagnoses.)
cipient age quirement	No age restrictions.	Under age 65.	Age 15 and older	Age 55 and older	65+ for elderly model or age 18-64 for physical disability model.	Birth to age 17	Birth to age 17	No age restrictions.

Program Characteristics	AFDC/HS Medicaid HMO	Primary Provider Program (PPP)	Independent Care (I-Care)	Program for All Inclusive Care for the Elderly (PACE)	WI Partnership Program	Children Come First (CCF)	WrapAround Milwaukee (WAM)	High Cost Case Management (HCCM)
Contracting entity	HMOs who are licensed by the WI Office of the Commissioner of Insurance. The HMO must also meet Medicaid's additional standards for quality assurance, cultural sensitivity, enrollment capacity and coordination of care.	Any willing Medicaid certified primary care physician in the following specialties, FP, GP, Internist, OB/GYN, and Peds., and Independent Nurse Practitioners. Can be associated with FQHCs and LPHAs.	Joint venture agreement between the Milwaukee Center for Independence, a community vocational training agency, and Humana WHO, an HMO.	Community Care Organizations, Inc., which operates Community Care for the Elderly (CCE) in Milwaukee. Elder Care Options in Dane County.	Elder Care of Dane Co., Inc. for elderly. Access to Independence, Inc. for physically disabled. (Center for Independent Living for Western Wisconsin (CILWW) for both elderly and physically disabled.)	Dane County Human Services	Milwaukee County Human Services	Contracts are pending.
isk sharing rrangement	Yes. Full capitation for all medical services covered by Medicaid except prenatal care coordination and common carrier transportation. Two capitation rates, one for AFDC, one for Healthy Start. Capitation rate varies by rate region. Ten rate regions divide the state.	No. Primary provider receives $3.00 PMPM and FFS payments for all medical care provided.	Yes. State pays a capitation rate of 100% of the Medicaid FFS costs per member month. ($553.24 Medicaid payment PMPM for CY '97.)	Yes. 95% of weighted average of NH cost plus costs of all other care. Medicaid shares risk for the first three years then PACE site assumes full risk. Medicaid payment $2,285.85 PMPM for Elder Care for CY '97. $2,131.71 PMPM for CCE for CY '97.	Yes. 95% of weighted average of NH cost plus costs of all other care. Solvency protection (stop-loss) system exists. Medicaid payment $2,131.71 PMPM for CCE for CY '97. $2,285.85 PMPM for Elder Care for CY '97. $2,916 PMPM for ACCESS for CY '97. CILWW receives $2,504 PMPM for physically disabled <65 and $1,993.36 for frail elderly 65+.	Yes. 95% of FFS costs for Mental Health Services. Dane Co. Human Services also provides payment to cover the non-Medicaid services. Approximately $3,600 PMPM for combined capitation.	Yes. 95% of FFS costs for Mental Health Services. Milwaukee Co. Human Services also provides payment to cover the non-Medicaid services. Approximately $4,900 PMPM for combined capitation.	No. Contract entity will receive a maximum of $80.00 per month per case accepted into program.
ayment rrangements for ther providers	Fully capitated for all specialty and ancillary medical services covered by the Medicaid program.	FFS payments for all necessary medical services. Specialists and ER must obtain a referral before treating.	Fully capitated for all specialty and ancillary medical services covered by the Medicaid program.	Fully capitated through contracted arrangements with Medicaid and Medicare.	Capitated for specialty and ancillary medical services covered by the Medicaid program, with some covered by FFS.	Through contracted arrangements with Dane County for MH services. FFS payments for all other necessary medical services.	Through contracted arrangements with Milwaukee County for MH services. FFS payments for all other necessary medical services.	FFS payments for all necessary medical services.

Program Characteristics	AFDC/HS Medicaid HMO	Primary Provider Program (PPP)	Independent Care (I-Care)	Program for All Inclusive Care for the Elderly (PACE)	WI Partnership Program	Children Come First (CCF)	WrapAround Milwaukee (WAM)	High Cost Case Management (HCCM)
ase Manager (CM) esponsibility	HMO must have system in place to ensure well managed patient care though assignment of PCP or other means, referrals for specialty care, and 24 hour urgent or emergency care.	PCP provides all primary care services and authorizes referrals for specialty care and emergency services. Personal care, therapies, transportation, community support programs, targeted case management, dental, chiropractic, podiatric, pharmacy, AODA, mental health and home health do not require a PCP referral.	Care coordinator assigned to each member. Care coordinators collect baseline data to support program effectiveness, conduct needs assessment within 30 days of enrollment and help member select PCP. Care coordinator can approve or disapprove certain services (e.g., ER visits) based on medical necessity.	The contracting entity has full responsibility and risk for providing and managing all care needed. Primary care is delivered directly by the PACE agency's own multi-disciplinary team in the community and in day health centers. Some services may be contracted out (HHC, meals, transportation) but PACE maintains full control of treatment plans and service delivery.	Contract entities must provide all services directly or create a provider network for services not provided directly. CM must provide for integrated service delivery and team-based care management. Nurse practitioners will link services across sites.	Dane County is responsible for the operational administration of the program and subcontracts for all necessary mental health services at whatever level of intensity required by the recipient, i.e., inpatient hospital, emergency care, outpatient therapy, residential treatment and therapeutic foster care, and case aide and in-home treatment services. Key service components are clinical case management, crisis services, intensive day treatment and school-based mental health services.	Milwaukee County is responsible for the operational administration of the program and subcontracts for all necessary mental health services at whatever level of intensity required by the recipient, i.e., inpatient hospital, emergency care, outpatient therapy, residential treatment and therapeutic foster care, and case aide and in-home treatment services. Key service components are clinical case management, crisis services, intensive day treatment and school-based mental health services.	CM firm will provide case management services to all recipients referred to the program. CM firm must assign a case manager within designated period of time after referral to program. One face to face contact at least every three months is required. Exceptions made at request of recipient.
ecipient Incentives	No copays.	24 hour nurse triage line available.	No copays. Care coordinator available 24 hours. Expansion of services beyond those offered in FFS system. Transportation arranged and paid for directly by the HMO.	Daily contact with care providers. Cannot be disenrolled if condition changes. Expansion of services beyond those offered in FFS system. Allows enrollee to stay at home. A multi-disciplinary team coordinates enrolees' health care.	Home care. No mandatory adult day care and physician assignment. Expansion of services beyond those offered in FFS system. Enrollee may continue to use current primary care physician. A multi-disciplinary team coordinates enrolees' health care.	No copays. Expansion of services beyond those offered in FFS system. Allows client to stay at home.	Same as CCF	Case coordinator available.

Program Characteristics	AFDC/HS Medicaid HMO	Primary Provider Program (PPP)	Independent Care (I-Care)	Program for All Inclusive Care for the Elderly (PACE)	WI Partnership Program	Children Come First (CCF)	WrapAround Milwaukee (WAM)	High Cost Case Management (HCCM)
ecipient articipation	Enrollee must obtain services through HMO providers.	Enrollee can choose PCP. Enrollee must obtain referral from PCP before seeking services from a specialist.	Enrollees receive a needs assessment within 60 days of enrollment. They must obtain services through I Care's provider network.	Enrollees are locked-in to PACE agency providers exclusively. Also attend adult day care.	Enrollees may retain their own physician. They use contract entity or subcontracted providers for all medical services.	Enrollees must use designated agency for all MH services.	Same as CCF	Enrollee must agree to participate in program.
overed services	HMO must cover all services which would be covered under Medicaid FFS.	Traditional Medicaid FFS coverage.	Traditional Medicaid FFS coverage. Also covers costs of social, recreational activities, and wellness programs.	Traditional Medicaid FFS coverage. Use Medicare and Medicaid funds to wrap around social services.	Traditional Medicaid FFS coverage plus services which are not covered by Medicaid, such as social services.	All necessary MH and AODA services including those not traditionally covered under Medicaid.	Same as CCF	Traditional Medicaid FFS coverage.
xcluded services	All services excluded by Medicaid program. HMO may elect not to cover dental services.	All services excluded by Medicaid program.		Housing is not a covered benefit.	Housing is not a covered benefit.	Physical Medical Services are covered through fee-for-service.	Same as CCF	All services excluded by Medicaid program.
urrent status	Approx. 60% of AFDC and Healthy Start eligibles will be enrolled in HMOs by May 1997. Savings of $16 million for non-expansion HMOs in FY '96.	5,669 enrollees and 179 primary providers as of March 1997	2,389 enrollees in February 1997	330 enrollees in Milwaukee as of December 1996. Estimated savings over $600,000 FY '95. In Dane County, 100 participants as of December 1996.	Two sites for elderly model with over 60 participants. Physical disabilities model began June 1996.	173 children served in the second year. Inpatient hospital days reduced from 3.3 to .8 per recipient per month. Estimated savings $150,00 CY '94.	Same as CCF	Contracts are pending. $540,000 is budgeted. Estimated savings is 5%.
lans for expansion	Statewide expansion will be completed in May 1997.	(Federal waiver expires on 5/29/97.)	Expansion of SSI managed care to two additional counties, Kenosha and Racine, is planned for January 1998.		Center for Independent Living for Western Wisconsin (CILWW), an additional site for the elderly and for the physical disabilities model, is being planned for May 1997.			

haracteristics	AFDC/HS Medicaid HMO	Primary Provider Program (PPP)	Independent Care (I-Care)	Program for All Inclusive Care for the Elderly (PACE)	WI Partnership Program	Children Come First (CCF)	WrapAround Milwaukee (WAM)	High Cost Case Management (HCCM)
rogram monitoring	HMOs must submit quarterly utilization and quality indicator data. Program and medical audits conducted by BHCF.	An internal BHCF workgroup has been established to evaluate this program.	HMOs must submit quarterly and semi-annual utilization and quality indicator data. Program and medical audits are conducted by BHCF. Human Services Research Institute (HSRI) of Massachusetts has evaluated the program using HCFA's Medicaid Statistical Informational System (MSIS), a brief encounter form, focus groups, and interviews with staff as data sources. HSRI will use I-Care's claims database and MMIS to analyze utilization. Also, the Social Security Administration will provide data on distribution by disability type of all eligible Medicaid recipients in Milwaukee County.	Abt Associates, Inc., is under contract with HCFA to evaluate the program using data collected from all existing On Lok and PACE replication sites. Data sources are: PACE applicant survey; Medicaid and Medicare claims and eligibility data; DataPACE system; and, interviews and site visits. Final report submitted to HCFA in Summer 1996.	An external committee is overseeing the research and evaluation components and has produced initial results. The research is intended to provide data on acute and long term care costs and patient outcomes and will provide information on quality assurance that can be incorporated into provider contracts and State Medicaid quality assurance systems.	A Task Force has been appointed by the County Executive to help assess the impact and performance of the program and make recommendations for necessary changes.	A Community Partnership team has been appointed to help assess the impact and performance of the program and make recommendations for necessary changes.	An internal BHCF workgroup has been established to evaluate this program.

Children Come First of Dane County provides individualized care

Providing appropriate and effective behavioral mental health care to children with severe emotional disorders is not easy.

Because these children are often difficult to control and can be a danger to themselves and others, they are often seen as a challenge too big for school systems, mental health agencies, juvenile justice systems, and their families each to handle alone. Often institutional placement for these children seems like the best solution.

However, one Wisconsin behavioral mental health program is having successful results treating children with severe emotional disorders.

By coordinating the efforts of school systems, mental health agencies, juvenile justice systems, and families, Children Come First of Dane County is helping many children receive the individualized, coordinated care they need to get better.

In many cases, the program's efforts are resulting in enough rehabilitation and developmental growth in the children to allow them to live in their communities instead of being institutionalized.

The framework for Children Come First of Dane County has been established by the Children Come First Act, which was passed in the Wisconsin 1987-1989 Budget Act. The act created a new section of the Wisconsin statutes, 46.56, and added amendments to other sections of the statutes.

The act prescribes how to develop a coordinated system of care in which multiple agencies work together to help children and families with multiple needs.

The act also authorizes public educational and human service agencies to collaborate in planning and providing services and directs the Department of Health and Family Services to provide technical assistance and statewide coordination for Children Come First programs throughout the state.

Through the Children Come First of Dane County program, everyone who has a role in helping the participating child comes together to develop the child's treatment plan. This includes both formal support providers, such as teachers, doctors, social workers, and psychologists, and informal support providers, such as family members, foster parents, and other individuals who play an important role in the child's life.

This group approach to developing the child's treatment plan helps facilitate agreement about the appropriate treatment for the child and what each member's responsibility is in providing that treatment.

The result is coordinated, consistent treatment tailored to the child's and family needs, a goal which is difficult to achieve if each agency is developing its own separate treatment plan for the child.

By including informal support providers in the development of the child's treatment plan, the program aims to ensure the family's needs are represented. An added advantage is that informal support providers will be able to offer continued support and guidance to the child after completion of the program.

Unlike many other behavioral mental health programs, Children Come First of Dane County provides individualized, family-driven care based on the child's and family's strengths. The program uses the "wraparound" philosophy of care described in the Children Come First Act.

The wraparound philosophy stresses the need for services to be based on the specific needs of the child and family rather than on predetermined service slots. This philosophy also grants the use of flexible, non-categorized funding to obtain unique but necessary services for the child and family, such as in-home assistance or recreational and instructional activities, that cannot be paid for through categorized funding.

An important aspect of the Children Come First of Dane County program is that it is one of Wisconsin's first behavioral mental health programs to successfully operate under a managed care system. Children Come First of Dane County has operated under a full-risk managed care system since 1994.

The current monthly capitation rate of $3,500 per child comes from a combination of sources, including the Department of Health and Family Services, the Division of Health, and the Dane County Department of Human Services.

The funds are used to subcontract for all necessary mental health, inpatient hospital, emergency care, outpatient therapy, residential treatment, therapeutic foster care, case aide, and in-home treatment services.

Although the program is costly, it is much less expensive than institutionalization, and the results are much better. The program has saved an estimated $96,900 in 1994 and $118,600 in 1995. In addition, since its inception in April 1993, the program has produced the following results:

- An 89% decrease in the delinquency rate of participating children.
- A rate of over 60% of children who are able to live in the community either independently or with families upon completion of the program.
- An average of 15% improvement per participating child on the child and family behavioral functioning scale.
- An over 90% satisfaction rate among families with the support received through the program.
- A decrease in the average monthly inpatient hospital stays per child from 3.3 days to .8 days.

Says Eleanor McLean, who oversees the Children Come First of Dane County program as Section Chief of the Child and Adolescent Unit of the Bureau of Community Mental Health (within the Division of Community Living; DHFS), "This wraparound process has proven invaluable in serving children with severe emotional disabilities and their families. It meets the Department's goal of keeping families together and children in their home community."

Currently, Children Come First of Dane County is serving 125 children. The enrollment capacity is 160 children.

Children must meet the following eligibility requirements to participate in the program:

- Be age 17 or younger. (However, children may remain in the program through age 18.)
- Be a resident of Dane County.
- Have at least one severe emotional disorder.
- Be at imminent risk of placement in a residential treatment center, psychiatric hospital, child caring institution, or juvenile correctional facility. ❖

Reprinted with permission from the February 1997 Forward *newsletter.*

Wraparound Milwaukee saving dollars, improving outcomes

Many Milwaukee County children with complex emotional, behavioral, and mental health care needs are receiving quality, individualized services, allowing them to live in their home communities instead of an institution, through the Wraparound Milwaukee program.

Wraparound Milwaukee is a behavioral mental health managed care program serving Milwaukee County children under age 18 who meet the following qualifications:

- Have a current diagnosable mental health disorder.
- Are involved in two or more Milwaukee service systems, including the mental health, child welfare, or juvenile justice systems.
- Have been identified for out-of-home placement in a residential treatment center, or could be returned from such a facility with the availability of wraparound services.

The program uses a treatment approach called "wraparound." This approach aims to determine what services a family really needs to care for their child, to identify the personal, community, and professional resources available to meet those needs, and to "wrap" the services around the child and family. This wraparound approach individualizes care rather than trying to fit a child into an existing service slot not specifically tailored to the child's needs.

Medicaid managed care children who meet the qualifications to participate in Wraparound Milwaukee are exempted from HMO enrollment and receive medical care through Medicaid fee-for-service during their participation in Wraparound Milwaukee.

"One of the nicest things about wraparound," says Ron Rogers, program supervisor of the care coordination program at St. Charles Youth and Family Services (an agency that provides wraparound services), "is that the family has a huge input into the child's plan of care."

Families enrolled in the program build a support team, which may include supportive people such as extended family members, neighbors, important teachers, and friends, along with professionals such as care coordinators, therapists, and probation officers.

"Ideally the team is made up of whoever the family wants on the team," says Rogers. "What's really neat about the whole wraparound process is that the team determines the child's treatment needs and the best way to meet those needs," he says.

Based on the child's and family's strengths and needs, the team develops the plan of care which draws upon existing resources available to the family as well as the services available through Wraparound Milwaukee.

The services available through Wraparound Milwaukee include:

- Intensive In-Home Treatment.

- Day Treatment.
- Treatment Foster Care.
- Medical Support.
- Outpatient Therapy.
- Mentoring.
- Respite Care.
- Crisis Beds.
- AODA Services.
- Special Therapies.
- Transportation.
- Job Training/Placement.

The program also provides care coordination services through both contracted agencies and through its own specialized care coordination unit called Stride, which combines care coordination with in-home therapy. In addition, there is the Mobile Urgent Treatment Team, which provides crisis intervention services.

Funding for Wraparound Milwaukee comes from three main sources:

- A $15 million federal grant from the Center for Mental Health Services. The grant was awarded in 1994 and is being used over a period of five years. This year's amount is approximately $3 million.
- A case rate of $3,300 per month per child paid by Milwaukee County's child welfare department.
- A Wisconsin Medicaid cap rate of $1,400 per month per Medicaid-eligible child.

Currently, Wraparound Milwaukee has 270 children enrolled in the program (approximately 75-80% of them are Medicaid eligible). Says Wraparound Milwaukee Project Director, Bruce Kamradt, the goal is to raise the enrollment to 400 this year.

The program has proved successful both in saving money and improving outcomes. Whereas residential treatment costs around $5,000 per month, per child, *not including* the cost of additional necessary mental health services, Wraparound Milwaukee provides comprehensive mental health care for less than what the cost of residential treatment alone would be.

The outcomes are better, too. According to Rogers, in relation to achieving improved outcomes, institutional care often does not fully prepare a child to return home. Wraparound, however, helps children develop their social competencies so they learn how to interact positively with their families and other people in their communities.

Steve Gilbertson, a psychologist with Wraparound Milwaukee, also agrees that outcomes through Wraparound Milwaukee tend to be better than through residential treatment. "Residential treatment usually relies on external structure to improve a child's behavior, but Wraparound helps a child learn self control."

Another positive outcome of the program has been the dramatic decrease in inpatient psychiatric care for these children. A recent report shows a 44.5 % decrease in Milwaukee County's child and adolescent psychiatric inpatient hospital stays. According to Kamradt, "That's the result of wraparound services such as the Mobile Urgent Crisis Team, which provides crisis intervention services to children and families and intervenes in situations where the children might otherwise be removed from their homes and hospitalized. Our Mobile Urgent Crisis Team now reviews all prospective inpatient hospital admissions of children and adolescents at Milwaukee County's child and adolescent treatment center."

Wraparound Milwaukee uses the same wraparound approach used by the Children Come First of Dane County program, featured in the February 1997, issue of *Forward*. Both programs have been successful serving children with severe emotional and behavioral mental health problems.

One obvious difference between the two programs is that Wraparound Milwaukee serves Milwaukee County residents, whereas Children Come First of Dane County serves Dane County residents. Another significant difference between the programs is that Wraparound Milwaukee is run directly by Milwaukee County, whereas Dane County contracts with a nonprofit organization, Community Care Management, to administer part of its program. (Community Care Management also provides some administrative support, including Management Information System services, to Wraparound Milwaukee.)

Project Director Kamradt says he is encouraged by the success of Wraparound Milwaukee and hopes to increase enrollment so more children may be served through the program. "Our strategy is to reinvest the dollars saved by using less institutional care into increasing Wraparound Milwaukee's capacity to serve more children," he says.

Anyone interested in learning more about Wraparound Milwaukee may contact the Wraparound Milwaukee Project office at (414) 257-7586 for more information. ❖

This article was reprinted with permission from the July, 1997 Forward *newsletter.*

Profile of a Wraparound child

Following is a description of a child currently participating in the Wraparound Milwaukee program. Many of the details of this case have been changed to protect the identity of the child and family.

Fifteen-year-old Marie (not her real name) was referred to Wraparound Milwaukee by her probation officer in November 1996.

She had been living in a residential treatment center for six months, but had been recently discharged because she had stolen a car. She was then in juvenile detention, on the verge of being sent to the state juvenile correctional facility.

Marie had a long history of delinquent behavior, including involvement in gang activity, problems with substance abuse, and expulsion from school.

Upon referral to Wraparound Milwaukee, a clinical psychologist with the program conducted an assessment of Marie and her family. Based on the assessment, he determined Marie could benefit from Wraparound services, and recommended her for Wraparound Milwaukee enrollment. Her enrollment was approved by the juvenile court.

At that point, the psychologist became the care coordinator (the one responsible for coordinating care) for Marie's case. He and other members of the Wraparound in-home treatment team began working with Marie and her parents to help mend their broken relationships.

The care coordinator helped Marie and her parents assemble a support team, consisting of Marie and her parents, the care coordinator, a child psychologist, representatives from school, treatment providers, family friends, and Marie's probation officer.

Through meetings together, the team developed a strength and need-based plan of care which drew from as many resources already available to the family as possible.

Marie's plan of care also made use of Wraparound services, such as mentoring. Marie was matched up with a 22-year-old female mentor who spends 15 hours per week with Marie. They go to museums, coffee houses, parks, etc.

The plan of care also required Marie to return to school. Since she had been expelled from the public school, the team chose a private alternative school for her to attend. Negotiations resulted in her public school district paying for her alternative school tuition and transportation.

Because Marie is musically inclined and expressed an interest in playing guitar, Wraparound also arranged for guitar lessons for Marie twice a week. This activity helps build Marie's confidence and encourages her in pursuing her positive interests.

Currently, Marie and her team are working on a drug relapse prevention plan. Marie is learning to manage her drug cravings and to recognize unhealthy/high risk situations. Random drug screens have shown her to be drug-free for several months.

Her relationship with her parents has improved. She is living at home, going to school, and maintaining a B-/C+ grade average. This is a big improvement, as she had been failing school prior to her enrollment in Wraparound Milwaukee.

Although Marie's initial costs in the Wraparound program were higher, the total cost of her current wraparound services is around $1,500/month. This covers the services of the care coordinator, psychiatric medication management, in-home individual and family therapy, mentor, and guitar lessons. In contrast, if Marie had been sent to jail, or had remained in a residential treatment center, the cost of institutional care alone would have run around $5,000/month, not including the cost of additional mental health treatment services. ❖

This article was reprinted with permission from the July, 1997 Forward *newsletter.*

CCE helps frail elderly keep independence

Note: In the January issue of Forward, we briefly outlined the Program for All-Inclusive Care for the Elderly (PACE) and Wisconsin Partnership Programs (WPP) operating in Milwaukee and Dane counties. This article takes a closer look at Milwaukee County's Community Care for the Elderly (CCE) and its PACE replication.

Frail older persons in Milwaukee County have access to a unique program which provides for their long-term health care needs. This program is called Community Care for the Elderly, or CCE, which replicates the PACE model, a managed care system pioneered by On Lok Systems of San Francisco.

CCE is a voluntary alternative to nursing home care for frail seniors who wish to remain independent. The program targets frail seniors whose physical and/or mental status make them eligible for nursing home placement. CCE program participants attend an adult day health center and receive comprehensive medical and social services while living in the community.

Community Care Organization (CCO), a private non-profit organization in Milwaukee, began operating CCE in 1990. CCE also operates WPP, a program for frail elderly persons and those with disabilities who would normally be placed in a nursing home or institution.

A distinctive feature of CCE is the multi-disciplinary team that coordinates the health of each participant. Members of CCE's multidisciplinary team work together to meet all the needs of the individual. The individual or family never needs to negotiate services with multiple providers and practitioners; the team takes care of everything. And because CCE caregivers have daily contact with enrollees, they can detect any subtle changes in condition and modify the individual's treatment plan accordingly.

Many of the services provided at CCE are provided at the program's adult day health centers. Participants in the program generally attend a day health center at least once per week. In addition to receiving health and social services, CCE's 340 PACE participants enhance their social life by joining a wide variety of activities offered at the center.

Services at CCE's adult day health care centers include the following:

- Breakfast.
- Lunch.
- Daily exercise.
- Medication administration.
- Nursing intervention and monitoring.
- Personal care assistance.
- Primary medical care.
- Psychosocial counseling and support.
- Recreational activities.
- Social services.
- Transportation.

CCE's staff consist of a variety of professionals dedicated to working with elderly individuals. Team members who serve at CCE's adult day health centers include the following:

- Activity coordinators.
- Center supervisor.
- Dietary personnel.
- Medical records personnel and medical assistants.
- Nurse practitioners.
- Personal care workers.
- Primary care physicians.
- Registered nurses.
- Rehabilitation therapists.
- Social workers.

"We provide about 50 percent of the home care [for participants] and contract for the rest," said CCO's Chief Executive Officer Kirby Shoaf. "We also contract for specialty physician services, hospital services, nursing home services, about 40 percent of our transportation, and many other services."

To be eligible for the CCE program, participants must be at least 55 years old, have long-term health care needs, live in Milwaukee County, be Medicaid and/or Medicare eligible, have potential for remaining in the community with assistance, and agree to receive all services from CCE or providers approved by CCE.

Funding for CCE comes via monthly capitation payments from Medicaid and Medicare for all eligible enrollees. Most participants who qualify for both Medicaid and Medicare pay nothing for the program. However, those who qualify for just one of these programs, or who fall into certain special categories, pay a portion of the premium. These funds are then pooled together to achieve maximum efficiency and flexibility in care planning.

Medicaid pays CCE a monthly, per-person capitation rate of $2,132 for PACE, while Medicare pays a monthly rate of $1,039. In return for this monthly premium, CCE is fully responsible for the physical, psychological, and social care of each patient.

Nationally, Medicaid capitation payments to PACE sites yield states a 5-15 percent savings relative to their fee-for-service expenditures for a comparable nursing-home certified population. Beyond these savings, PACE offers policy makers a more comprehensive and less costly alternative to constructing new nursing home beds.

Because PACE is a managed care model that enrolls only frail older persons, assuring enrollees' quality of care is extremely important. In 1993, the Community Health Accreditation Program reviewed five PACE sites and found the quality and coordination of enrollee care to be "exceptional." In 1995, the National PACE Association received a grant from the Robert Wood Johnson Foundation to develop standards and an accreditation mechanism for PACE.

CCO is a not-for-profit nonstock corporation which provides the following programs in addition to CCE: Grandfathered CCO Demonstration Program, Comprehensive Community Care Program, Manitowoc Case Management Program, Elder Abuse Reporting System, Elder Abuse Direct Services, and Care Consulting Services.

Over the past four years, the CCE program has experienced an average annual growth rate of 36 percent and has nearly quadrupled in size. ❖

Reprinted with permission from the March, 1997 Forward *newsletter.*

Elder Care Partnership serves elderly, individuals with disabilities

In most capitated managed care programs, the enrollee must choose a physician among those associated with the managed care organization's network. While this limitation may not pose a problem for most enrollees, it can be hard on the elderly and physically disabled, many of whom have seen a certain provider for many years and have chronic medical problems and multiple diagnoses.

Elder Care of Dane County, Inc. offers a solution to this problem. The Elder Care Partnership program, which began in January of 1996, offers enrollees the many benefits of a managed long term care program, yet allows them to retain their primary care physician. This program is based on the Wisconsin Partnership Program (WPP) model developed by the DHFS, Elder Care of Dane County, the UW School of Nursing, and Access to Independence.

The Wisconsin Partnership Program is voluntary and serves the frail elderly and people with physical disabilities. The program integrates health and long term care support services and includes home and community-based services, physician services, and all other medical care. The program targets those who are nursing-home eligible yet who would like to remain in their homes.

A key element in the Elder Care Partnership program is the team-based approach to care management. Four core team members coordinate care for each Partnership enrollee. These team members and their primary responsibilities are outlined below:

- Primary Care Physician - Provides primary health care and supervises all medical intervention performed by the nurse practitioner.
- Nurse Practitioner - Conducts assessments, participates in care plan development, monitors ongoing clinical status, responds immediately to acute care problems, provides participant/care-giver education, and acts as the liaison between the primary care physician and the rest of the team.
- Social Worker - Conducts psychosocial and economic assessments, manages referrals, counsels, and coordinates community services.
- Home Care Nurse - Conducts assessments of functional limitations and safety issues, and supervises personal care workers in the home.

The eighty-plus individuals who are currently enrolled in the Elder Care Partnership program have an average of eight chronic conditions and take an average of six medications. "We try to manage their symptoms in such a way that the person can be cared for in the community, despite these medical conditions," Elder Care's Executive Director Jim Kellerman said.

Those eligible for Elder Care Partnership include frail elderly and disabled persons who are 55 years or older, live in Dane County, have chronic medical conditions, need assistance to stay at home, and are financially eligible.

Elder Care of Dane County is responsible for all daily administrative and clinical aspects of Elder Care Partnership, including maintaining contracts with all participating physicians and other providers, thus offering a full scope of health care and long-term support services.

At the current time, there is no accreditation process for WPP. "Our program is now evolving the standards; we are acting as a laboratory to figure out what the standards (of accreditation) should be," Kellerman said. "Currently, we have a vigorous Quality Improvement/ Quality Assurance plan which we implement."

Funding for the Elder Care Partnership program comes from Medicaid, which pays Elder Care Partnership 95% of what it costs to serve a nursing home-eligible senior in a fee-for-service environment. Enrollees keep the first $600 of this Medicaid capitation for housing costs, and the remainder of the fee is used for each enrollee's care. Under Medicaid fee-for-service, Elder Care Partnership coordinates in- and outpatient hospital, lab, x-ray, and home health services. The Partnership team also manages all of the Medicare-funded services, which at this time remain fee-for-service; in 1998 these Medicare funds will also be capitated.

Elder Care Partnership is a collaboration between Elder Care of Dane County and the Wisconsin Partnership Program. Elder Care Partnership is administered by the Wisconsin DHFS under a Wisconsin Medicaid Program contract. ❖

Reprinted with permission from the April, 1997 Forward *newsletter.*

Milwaukee County residents with disabilities rely on I Care

Medicaid recipients with disabilities in Milwaukee County now have a navigator to guide them through the waters of managed care. That navigator is I Care.

I Care, or Independent Care, has been operating since 1994 when the Department of Health and Family Services received a Health Care Financing Administration research and demonstration grant to begin a project to help developmentally disabled Medicaid recipients.

The I Care program provides coordinated medical and social services to people with disabilities who live in Milwaukee County. Services are arranged for each recipient by a care coordinator. The care coordinator helps each recipient do the following:

- Choose a doctor and hospital.
- Find appropriate medical care.
- Find services after a hospital stay.
- Sign up for social services.
- Find community services.

I Care members receive the same medical services as those covered by Medicaid. In addition to these services, I Care offers recipients the following:

- *A Care Coordinator:* This individual works to get the member and his or her family the services they need.
- *A Primary Care Doctor:* Primary care doctors are chosen for their knowledge of, and desire to work with, persons with disabilities.
- *Hospital and emergency services:* Each member's care coordinator or physician arranges hospital stays.
- *Wellness Programs:* I Care offers programs to help members stay healthy and a newsletter with health advice and program descriptions.
- *Social Services:* Members may access social services via their care coordinator. This coordinator helps the member find the services he or she needs.

In addition to standard medical services, care coordinators can help members arrange dental and eye care appointments, mental health, alcohol, and drug abuse treatment, pharmacy services, medical supplies and equipment, homecare services, nursing home and hospice care services, and transportation.

Care coordinators collect base line data to support program effectiveness, conduct a needs assessment within 30 days of enrollment and help the member select a primary care physician. The care coordinator can also approve or disapprove certain services (for example, E.R. visits) based on medical necessity.

Those eligible for I Care include people who receive Supplemental Security Income and Medicaid under Medical Status code 21, who live in Milwaukee County, and who are at least 15 years old.

For more information about I Care contact Mike Fox at 608-266-7559. ❖

Reprinted with permission from the December, 1997 Forward *newsletter.*

PACE/Partnership programs guide long term care

Two Wisconsin Medicaid programs are serving as forerunners in the state's long term care redesign plans.

The PACE and Wisconsin Partnership programs, while sharing similar goals and target groups, are two distinct managed care programs that seek to provide comprehensive care to the frail elderly and, in the case of the Wisconsin Partnership Program, the physically disabled.

PACE stands for Program for All Inclusive Care for the Elderly. The program began in 1990 in Milwaukee under the name Community Care for the Elderly (CCE) and expanded to include Elder Care of Dane County in 1995. The PACE program is a congressionally authorized replication of the managed care system pioneered by On Lok Senior Health Services of San Francisco, CA. On Lok is a nationally recognized program for frail elderly persons.

The Wisconsin Partnership Program (WPP) began when the Bureau of Long Term Support within the DOH, DHFS, was awarded a grant by the Robert Wood Johnson Foundation in 1994. WPP is a model used to provide services for the frail elderly and persons with physical disabilities. Currently, there are three active WPP agencies in Wisconsin. These are Elder Care of Dane County in Madison, which began operating WPP in February of 1996; Community Care for the Elderly in Milwaukee, which began operating in May of 1996; and Access to Independence in Madison, which began operating WPP in the summer of 1996.

Both programs are voluntary and are designed to provide frail elderly persons (and in the case of WPP, persons with disabilities) with the support needed to avoid being placed in a nursing home. Both programs accomplish this goal by coordinating local medical and social services.

Community Care for the Elderly, Elder Care, and Access to Independence have contracts with the Department of Health and Family Services to provide Medicaid services to their target groups. They operate with capitated funding, but reimburse some inpatient and hospital services, lab and x-ray fees, and home health services on a fee-for-service basis. ❖

Reprinted with permission from the January, 1997 Forward *newsletter.*

Ms. CHRISTENSEN. Thank you.

I think Jane is going to tell us about some of the other States and what they are doing.

STATEMENT OF JANE HORVATH, DIRECTOR OF MEDICAID PROJECTS, NATIONAL ACADEMY FOR STATE HEALTH POLICY

Ms. HORVATH. I am going to take probably a more shotgun approach to this issue this morning. I appreciate the opportunity to be here, and thank you for inviting me.

The National Academy for State Health Policy is a nonprofit organization based in Portland, ME. We receive most of our funding through foundations and do work with specific States around issues. We have done a lot of work around enrollment of elderly and disabled populations into Medicaid managed care programs for a number of years, and I myself am working on a project with another very special population within Medicaid, which is foster care children enrollment into Medicaid managed care. I am working on a Cummings Foundation project specifically with five States, building interagency teams, to look at how best to do this for I think what is arguably the most vulnerable of generally vulnerable population of Medicaid clientele.

I want to just give you some background, and I really wanted to zero in on special needs adults and children within Medicaid and, in our experience, the things that States have to consider, I want to give some brief examples of how States have approached the issue of Medicaid managed care and vulnerable populations.

I have some handouts with charts that I'm not going to go into detail on, but just reference.

Our records show that as of January of this year, there were 26 States that were enrolling elderly and/or some portion of disabled populations into risk-based Medicaid managed care. I think what is most important to keep in mind when you think about this population and you think about what States are doing is to understand that currently, of the 38 risk-contracting States, that most Medicaid managed care programs as of yet do not integrate long-term care or long-term support under a capitated program, which becomes a crucial aspect when you are talking about children and adults with special health care needs.

Concurrent with that, the other important caveat to keep in mind is that most Medicaid programs, whether or not they are enrolling elderly and disabled, do not integrate Medicare into their system of care. It is an extremely difficult thing to do. It is not for lack of desire on the part of State Medicaid agencies, but that's another whole issue of politics and policies. You need to keep in mind because both of those caveats when long-term care services and supports are not integrated, people have to walk through at least two systems, and it can create cost-shifting incentives that did not necessarily exist in the fee-for-service system. When Medicare is not integrated, it can certainly create cost-shifting incentives that did not exist under fee-for-service.

So we try to keep these things in mind when we are thinking about enrolling special needs populations, elderly/disabled adults and children, into Medicaid managed care. These issues are not necessarily relevant to the AFDC population. So it is a new set of issues for States that they are attending to.

In this packet, which I hope you all have, by way of background information, I have put together a chart on the state enrollment carve-out policies. The chart shows that most of the States are not enrolling these populations. There are a number of States that actually prohibit enrollment, whether their program voluntary or mandatory, of a variety of special needs populations: the dually eligible receiving home and community-based long-term care services, people receiving institutional long-term medical, children in foster care, and subsidized adoption.

There is another chart that you might want to look at concerning the eligible population, and which is demonstrative of some of the points that I want to bring home today, about the connection to the long-term care and the service support system. There is a chart in here that shows the number of States that are enrolling dually eligible persons; whether that enrollment is voluntary or mandatory; and the linkage of the health care system in which they are enrolled to the long-term care system. So you can see that some States are ahead of others in creating that linkage, but all States have got to address that linkage in one way or another. This highlights how they do it.

I have another chart in here about the number of States that are enrolling elderly and adults with disabilities. The States that are enrolling children with disabilities are not included in this chart but they are few in number. This chart gives you a view of some data we collected on a survey that we did which captured the extent of mental health coverage under a risk contract, the extent of nursing facility coverage, and the extent of home health coverage under risk contract. So you can see, again, what the connection is between these other services and medical care for special needs populations.

I also want to turn your attention briefly to a list of the kinds of issues that States need to consider as they look to expanding risk-based contracts and to include these populations. I purposely left rate-setting off of this list. I felt fairly certain that that had been covered somewhere before in these forums; it always is.

Ms. CHRISTENSEN. We will probably do a hearing on rate-setting and a couple other big issues.

Ms. HORVATH. The first issue, I think, outside of rate-setting that States need to consider is coordination of services across systems. The special needs populations are dealing with a variety of service systems: long-term care, school-based systems for children with special educational needs, case management. So many of the special needs population adults and children are working in multiple programs with multiple case managers. State program policy needs to consider this fact and decide how it should be handled as the responsibility of the HMO or not.

Also, I would like to mention the State of Utah and their foster children enrollment in Salt Lake City. How they have addressed this issue of case management is they have a case manager outside the HMO. They do not require the HMO to coordinate services, but they have an outside case management nurse for these children who coordinates their health services within the HMO, does the follow-up and whatever else needs to get done to make sure that these children are accessing medically appropriate services. Also, that nurse case manager coordinates the rest of the services that the children need and receive. The nurse case management role is being extended to include all the mental health services as well. I think that's a very interesting idea of taking it out of the HMO.

The other issue that becomes significant in program design, is the Medicaid funding and who is responsible for what. It has been a real eye-opener for the Medicaid sister agencies in many States to learn or realize, extent to which they are reliant on Medicaid funding for their services, including Part H, IDEA, mental health system and what it may mean. It really becomes a real threat if Medicaid includes that funding in an MCO capitation and moves those services outside to an MCO. How this funding/capitation issue is handled is typically through negotiation. Medicaid agencies need to be very sensitive to the potential effect of pulling all of these service dollars out of different agencies and handing them over to the HMO.

I am going to turn next to the issue of physical access which becomes a big issue in the context of special needs populations with disabilities. States have learned—Massachusetts springs to mind right away—that they really ought to make sure their HMOs or their MCOs meet physical access standards for the doctors' offices in their network. In Massachusetts I believe physical access is actually part of their quality assurance and their onsite monitoring. They go out and check for physical access now that they are enrolling special needs populations.

Network composition can be different when you enroll special needs groups. There is the standard issue of number and type specialists, but also States can consider if there are generalists experienced with treating the populations being enrolled. Pediatricians who are familiar with the foster care caseload, for instance, come to mind. Children in foster care are different than non-foster care population of AFDC children. Even though you need pediatricians in any network, you may need or want providers who are familiar with the foster care caseload and how to treat them if you enroll this group. So network composition standards may change.

Wisconsin has some contract language around this composition issue, and I think States are evolving in their thinking. Maryland, I understand, has some very good regulations on what they are expecting of their contractors in terms of provided expertise—and not necessarily specialization, but expertise and familiarity in treating the foster care caseload.

In regard to covered services, I think a definition of medically necessary and appropriate services becomes far more important when you are talking about enrolling these populations than it heretofore has been for States. There are a lot more potential gray areas than with the AFDC/TANF population. The fundamental issue is who is responsible for providing and paying for what.

I also wanted to just say, too, one way states have sought to address issues of network composition, assuring access, and provider expertise or specialty in certain conditions is to encourage formation of MCOs which are the traditional providers for this population of people with special health care needs. William talked about including these specialty providers, or community and traditional providers, in MCO networks, and other States such as Rhode Island are actively encouraging the formation of the traditional providers into a risk-taking entity itself. Encouraging formation at MCOs among traditional providers creates another whole set of considerations that, during the question and answer period, maybe we can get into.

I think the other thing that enrolling special needs groups brings to the fore is the need for a lot more interagency collaboration at the State level. Maryland has talked about that; Barbara mentioned how they are working. What she didn't mention is how much they are working with the Department of Social Services around the enrollment of foster care children. State agencies should collaborate on program design to determine what services are in, what services are out—and how to shape the quality oversight system by drawing on the expertise of sister agencies that have been caring for these populations and overseeing the service providers themselves, where Medicaid has not had that role before.

Another important issue is outreach and education. States are taking different approaches to this varying population of special needs adults and children that is very different than how they work with their AFDC population.

A specific example is Oregon, which hired a contractor that they no longer use now that the program is up and running and there is general familiarity with it in the different communities. But they hired a contractor who specifically charged with going out and educating the community and community representatives and helping people make a choice of managed care plans. Ultimately, the actual enrollment of these people had to go through the State to be effectuated. That contract has since terminated, but it was very specific around SSI-related populations.

Tennessee has a contractor whose [inaudible] got a little nutty given the startup of TennCare and the great need, but is now being moved back to its original purpose. It is a hotline essentially, kind of a grievance and complaint, not an ombudsman, but a grievance complaint resolution community outreach hotline specifically for SSI-related. Those are the people who get the number. It was TennCare's way of acknowledging the specific need around finding doctors who will treat various special needs, enrolling populations, et cetera.

Oregon, again, has an ombudsman program that is only for SSI-related populations. It is a very specifically tailored program for a specific population, addressing very specific needs.

Maryland and Florida are the States I am aware of—I think that there are others now—that have done very specific outreach to foster care parents, foster care caseworkers, and foster care institutional providers about how managed care works, what it means, how you enroll, how you disenroll, and how to work with the system. This outreach has occurred county by county across each State, meeting by meeting, outreach programs, these States felt it was the type of effort really was important to make the system work for these kids, and because the folks who care for these kids need to really know how to access and use the system.

Other foster care special arrangements around enrolling foster care children have some applicability to thinking about the issues of special needs groups. In Oregon, they allow the Department of Social Services caseworkers to be the responsible party for enrolling these children in the appropriate HMO, or making the decision not to enroll these children, so that when these children change placements, it is the caseworker responsible for their case who actually goes into the computer and does that changing enrollment. This way, there is no lag time, which can actually be a very big problem as these children's placements change, as they frequently do, making sure that their medical home moves also in an as appropriate and quick a manner as possible.

On the quality assurance side, there is a project going on in Connecticut looking at encounter data from an HMO and running reports along the lines of EPSDT, early periodic screening, diagnosis and treatment, for children, and they are turning most of the reports back to the Medicaid agency, to the HMOs. They are going to have a tickler system in place for children who have not seen a provider according to the periodicities. A subset report for children in foster care is also produced and sent to the child welfare agency.

We think it is most important [inaudible] out of that specific report on foster care kids of the special needs population that deserves special looking into. It is what they alluded to, having a quality assurance system that does sampling. I don't believe that this is a sample-based thing; I think it's an encounter-based system that is not aggregated ultimately in the report. So that it can be done, and I believe the reports go to the HMOs, but I know they go to the Department of Social Services for follow-up with the caseworkers, so that the caseworker stays involved.

So I think that there is a lot going on out there. I think in terms of the State of the States, the State is [inaudible]. [Inaudible] because these are very high-cost populations. They remain generally out of the Medicaid managed care risk-based programs since their inception, and States are now turning their attention to them, and they are learning as they go along, as they kind of always have; they are learning from each other. I think we are going to see a heck of a lot of evolution in every component and aspect of Medicaid risk-based contracting for these populations in the next few years. There is going to be a lot of innovation to try.

[The prepared statement of Ms. Horvath follows:]

NATIONAL ACADEMY
for STATE HEALTH POLICY

Enrolling People with Special Needs

into

Medicaid Risk-Based
Managed Care Programs

Senate Aging Committee Forum

July 22, 1997

Jane Horvath
National Academy for State Health Policy

50 Monument Square, Suite 502 Portland, Maine 04101 Tel [207] 874-6524 Fax [207] 874-6527
Email: 73612.316.@compuserve.com

As of January 1997:

26 States enrolled elderly and disabled into risk-based Medicaid managed care

but

Most Medicaid programs do not integrate coverage of Long Term Care or Supports

and

Most Medicaid programs do not integrate Medicare into the risk-based health care system

National Academy for State Health Policy, 1997

Enrolling Special Needs Populations in Medicaid Managed Care

Considerations:

1) Coordination of services across systems
    - case management
    - special education system services (IDEA, Part H)
    - long term services and supports system

2) Medicaid funding -- who is responsible for what?
    - mental health
    - education system
    - MCH

3) Assuring access
    - physical access
    - network composition of specialists and others with appropriate experience
    - necessary covered services

National Academy for State Health Policy, 1997

Enrollment Carve Out Policies as of 6/96

Category	# of States Prohibiting Enrollment[1]	# of States Permitting Disenrollment[2]
Dually eligible	21	5
Receiving home/community based long term care/services	19	3
Receiving institutional long term care	28	7
Receiving long term community-based medical services	6	3
Receiving long term mental health services	12	2
Foster Care Children	16	6
Special Needs Children	6	3
Special Needs Adults	4	n/a
Subsidized Adoption	n/a	5

There were 38 states with risk-based Medicaid managed care programs as of 6/96:

1 Applies to either mandatory or voluntary enrollment programs

2 Applies to mandatory enrollment programs

National Academy for State Health Policy, 1997

Medicaid Managed Care Program Characteristics in States Enrolling Dually Eligible Persons in Health Programs

State	Medicaid DE Enrollment Policy[1]	NF or LTC Service covered Under Risk	Connection to LTC Service System
AZ	Mandatory	full LTC	LTC system is risk-based and comprehensive & linked to acute care system
CA	Voluntary in all but 5 counties	limited NF, LTC capitated by state in 3 of 5 mandatory cos	in all but 3 counties, disenrolled from risk after 60 days NF care
CO	Voluntary	Limited NF/no LTC	LTC on FFS, remain in HMO for health
FL	Voluntary	6 months NF/no LTC	disenrolled from risk after 6 mos NF
GA	Voluntary	no NF/no LTC	disenrolled from risk if enter NF
MD	Voluntary	no NF/no LTC	disenrolled from risk if enter NF
MI	Voluntary	no NF/no LTC	disenrolled from risk if enter NF
MN/ PMAP	Mandatory	no NF/some home based care	LTC on FFS, remain in HMO for health
MN/ MSHO	Voluntary	6 mo NF, and HCBC[2]	after 6 mo NF: LTC on FFS, remain in HMO for health
NV	Voluntary	LTC up to $10000/individual	disenrolled from risk if cap is reached
NJ	Voluntary	no NF/no LTC	disenrolled from risk if enter NF
NY	Voluntary	no NF/no LTC	disenrolled from risk if enter NF
OR	Mand. (Vol. for some DE)	Limited NF/no LTC	LTC on FFS, remain in HMO for health
PA	Mand/Vol by geography	Limited NF/no LTC	disenrolled from risk after 30 days NF
TN	Mandatory	no NF/no LTC	LTC on FFS, remain in HMO for health
UT	Mandatory	Limited NF/no LTC	HCBC recips stay in risk HMO; disenrolled from risk after 30 days NF
WI/P[3]	Voluntary	full benefits	LTC system is risk-based and comprehensive
WI/I[4]	Voluntary	90 days NF	disenrolled from risk after 90 days NF

1. Affecting Medicaid services only.
2. HCBC = Home and Community Based Long Term Care
3. WI Partnership Program: NF-eligible elderly and disabled adults. All benefits coordinated by the program, although particular long term care services may be under fee for service.
4. WI I-Care Program: Disabled Adults

National Academy for State Health Policy, 1997

Characteristics of Medicaid Risk Enrollment for Elderly and *Adults* w/ Disabilities as of 1/97

State	Enrolled Groups (E, D)	Vol./Mand. Enrollment	MH Coverage Scope	NF Coverage Scope	Home Health Coverage Scope
AZ	E, D	M	Separate, Full	Separate, Full	Full
CA	E, D	M[a]	not separate, scope unclear	Limited	Limited & Full (by contract)
CO	E, D	V/M[b]	Separate,Ltd	Limited	Limited
DE	D	M	Limited	Limited	Full
FL	E, D	V/M[c]	Separate, Limited	Limited	Full
GA	D	V	Full[d]	Not Covered	Full
IA	D	M	Separate, Full	Not Covered	Not Covered
MD	E, D	V	Full	Not Covered	Full
MA	E, D	V/M[e]	Separate, Full	Limited	Limited
MI	E, D	V/M[f]	Full	Not Covered	Limited
MN/PMAP	E	M	Full	Not Covered	Full
MN/MSHO	E	V	Covered	Limited[g]	Full
NE	E,D	M	Separate	Not Covered	Full
NV	E	V	Not Covered	Limited	Not Covered
NJ	E, D	V	Not Covered	Not Covered	Not Covered
NY	D	V	Limited	Not Covered	Full
OH	D	V	Limited	Not Covered	Full
OR	E, D	M	Separate,[h] Limited	Limited	Limited
PA	E, D	V/M[i]	Separate, Full	Limited	Full
SC	D	V	Limited	Limited	Not Covered
TN	~~E, D~~	M	Separate	Not Covered	Covered
UT	E, D	M/VI	Separate	Limited	Covered
VA	E, D	V/M[k]	Limited	Not Covered	Full
WA	E, D	M	Separate, Limited	Not Covered	Full
WI	E, D	V	Full	Full	Full

E = Elderly D=Disabled
Separate = separate risk contract from general HMO contract
Limited = limited benefit within general HMO contract
Full = full benefit within general HMO contract
V= voluntary enrollment for these groups **M**= mandatory enrollment for these groups

National Academy for State Health Policy, 1997

a. some counties

b. mandatory enrollment in MH contract when enrolled in PCCM program

c.mandatory enrollment in MH risk program for enrollees of PCCM program.

d.inpatient only

e.mandatory enrollment in risk mental health program for PCCM enrollees.

f.enrollment policy varies by area of the state

g. full long term care benefits other than NF.

h.Separate risk contract for PCCM enrollees.

i.Varies by location.

j. depending on location and whether enrolled in PCCM (for mandatory MH risk enrollment).

k.depending on location

National Academy for State Health Policy, 1997

Ms. CHRISTENSEN. Steve.

STATEMENT OF STEPHEN A. SOMERS, PRESIDENT, CENTER FOR HEALTH CARE STRATEGIES, INC.

Mr. SOMERS. Thank you, and good morning. I am Stephen Somers, and for the Hill staffers among you, you have in Jane Horvath and myself two former Senate staffers who are examples of what your future might be like—you too may be able to testify before a panel on managed care at the Senate Special Committee on Aging. It is a real pleasure to be here.

It is an honor as well to be here with Bill Scanlon and Jane, because they represent two of the supreme catalogers of what is going on across the States with respect to Medicaid managed care. I turn to the GAO and to the National Academy for State Health Policy constantly for information about where particular States stand, so I commend to your attention their materials.

It is always a pleasure to be on a panel with officials from Wisconsin and Maryland. I worked at the Robert Wood Johnson Foundation for many years, and for health care philanthropy, Wisconsin and Maryland are two States that are constantly seen as lighthouses or beacons, which is to say leaders, in progressive model development and innovation. It also means that they get all the grant money, too, so I expect to be hearing more from Wisconsin and Maryland in the future.

The Center for Health Care Strategies is a nonprofit organization running two major programs for the Robert Wood Johnson Foundation (RWJF) and also one for the Annie E. Casey Foundation.

There are two programs for RWJF. One is called the Building Health Systems Program—actually, Wisconsin has gotten substantial funding under that program from the Foundation—and the Medicaid Managed Care Program. Both of them are focusing on how to make health systems work better for people with chronic health problems.

As you probably know, the Robert Wood Johnson Foundation is a large health care philanthropy. It spends about $250 million a year on demonstration projects training, evaluation and research programs. A lot of them are large multi-site national programs.

The Medicaid Managed Care Program (MMCP) is just one of them, and I am going to focus the remainder of my time upon that program, which is described in your packet, and for which there is a Request for Proposals (RFP) attached.

The program is a $21 million national program, the goal of which is stated in your material, to make managed care work for Medicaid recipients, especially those with chronic health conditions. I would very much agree with what Peggy Bartels of Wisconsin said about Medicaid managed care in particular having the opportunity to lead the rest of the managed care marketplace with respect to serving these populations. This is because the commercial plans just have not served these populations before, and Medicaid has the kinds of requirements and attention to quality issues that should serve as a guide for all other managed care enterprises serving disabled populations.

The objectives of the MMCP are to build capacity among the purchasers—principally the States and, to some degree increasingly, counties as well—of managed care, and to develop models of managed care for vulnerable populations. As Jane was saying, there are almost inevitably going to be more models; as States begin to serve these populations with more and more intensity.

One of the other tools that we have available in the MMCP is something that we are calling a "readiness assessment." This means that we go out to States, and we ask them to tell us what they think they know how to do with respect to Medicaid managed care, particularly for special needs populations, and where they might need help. We have been to States ranging from Kansas to Massachusetts in terms of their experience with Medicaid managed care. In some States, that experience level is still very, very little; there hasn't been much done. Obviously, in others, such was Wisconsin, there is a tremendous amount that has been done.

In Kentucky, which is about to embark on a major and unique Medicaid managed care arrangement, we determined together with us that Medicaid staff really knew very, very little about how to do quality assurance in managed care. They had nobody who had ever worked in this area. This is a prime example of a term you probably hear a lot—the "paradigm shift,"—that is being required of State Medicaid agencies moving from fee-for-service to managed care. As a result of our readiness assessments in Kentucky and other States, we have developed an education module for States to provide basic training on quality assurance. We intend to make this available to a number of States individually or in regional meetings after consulting with HCFA's Technical Assistance Group (TAG) on Quality.

We also support a large number of policy studies. I think Bill and Jane both mentioned the carve-out issue. That was the subject of the first publication that we have sent out, done by MedStat. It reviews the major decision issues that States must consider in deciding whether to carve out populations under Medicaid managed care.

We are also about to release studies on rate-setting and risk adjustment by Rick Kronick and Tony Dreyfus who have worked in a number of the States that have been mentioned today: e.g. Wisconsin, Colorado, Massachusetts, etc. There is a big study on enrollment by Mary Kenesson which we are going to publish soon. We have also asked her to do a special supplement on enrolling special needs populations, because there is a very different need there. Some States are contracting with consumer organizations representing the various special needs populations to assist in the enrollment process. This is going on in Oregon; and New Mexico picked up the concept from a GAO report.

I wanted to mention a few of our model development and demonstration grouts. One interesting one, given some of the points that Jane was making, is to a county in Washington State, Clark County, which is north of Portland, to try to integrate all the funding streams that serve Medicaid populations into a single, integrated model, where you would take various funding streams, mental health, mental retardation, long-term care—plus Medicaid and create a single capitation for those populations. This is very much in the field of dreams stage, but it is something that is a very intriguing notion to consider.

I will also just mention that in your packet, there is a page about our Web site. Several panelists have mentioned the contracting study that was done by Sara Rosenbaum at George Washington University. Those of you who have seen this document know that it is 2,300-pages long. We are offering you the opportunity to give up carrying it around, because you can get it on the Web site in searchable fashion much more quickly.

In sum, we are working in about 20 States at this point under MMCP. In terms of what are we finding out there, I would like to make just a few summary observations. The purchaser's capacity is extraordinarily uneven. You have before you today two States—Maryland and Wisconsin—that really have a great handle on purchasing issues. There are States that come to mind where they have just two or three professional staff working on Medicaid managed care. This is too complicated an undertaking for such sparse staffing, even in a sparsely populated State.

We are working with relatively rural counties in Minnesota that probably have ten times more staff working on Medicaid managed care. So the range is really enormous in terms of capacity, and part of what we are trying to do in MMCP is to try to build the purchasing capacity of States.

It has also struck me as I have been doing this work that there are a number of Federal agencies with "offices of managed care," like HRSA and CDC and SAMSHA and CSAT—you name it, they have an office of managed care—to help their constituencies cope with the coming of Medicaid managed care.

HCFA, on the other hand, provides remarkably little direct technical assistance to State Medicaid agencies. I am sure there are historical reasons for that gap, but it seems out of kilter. There are probably people in this hearing room who could do something about this imbalance.

The other issue that I want to raise is the fact that there are very few models for special needs populations. I am actually quite taken aback that no one has mentioned the Community Medical Alliance (CMA) in Boston as a premier model of managed care for special needs populations. It serves people with end-stage AIDS and severe physical disability. Several attempts were made to replicate the model under the Medicaid Working Group initiative funded by RWJF and the few charitable trusts, but they have been very slow to take hold. Even in Boston, CMA is only serving 190 people or so, and we are talking about thousands and thousands, if not millions, of people who will need to be cared for in such model special needs plans.

In sum, there are few models; that is why we are in this business. One of the emerging issues that may complicate the development of managed care for special needs populations is that counties are going to play a much more significant role than most of us anticipated. This is all part of the "devolution trend," particularly in States where counties are enormously important politically. Minnesota is just one example. Minnesota could end up with 87 different enrollment brokers because 87 different counties may insist on having the enrollment broker responsibility. That is not necessarily the most efficient way to do business but that may be how it will get done in Minnesota.

In other States devolution is more a matter of way passing off the risk and the responsibility to the counties. If there is no capacity at the county level this becomes another area of concern.

There are a few other emerging issues that I would just like to mention. Clearly, quality assurance is something that many States need a huge amount of help with——and we intend to work in that area.

Further, there are really very few performance standards for serving special needs populations. This is another arena that we also would like to work on.

Finally, the managed care marketplace is in enormous flux. There may be 19 managed care organizations in Wisconsin all of whom are willing to play. But in a lot of States, commercial managed care organizations are leaving the Medicaid market; in others, the managed care organizations that are based within the traditional community provider network—community health centers and so on are not succeeding. Who is going to be left providing Medicaid managed care, particularly to the special needs populations? Bob Hurley is doing a study on the Medicaid managed care markeplace for us right now, and it should be a very, very interesting sport.

Thanks very much.

[The prepared statement of Mr. Somers follows:]

Forums on Managed Care for People with Special Needs

U.S. Senate Special Committee on Aging
Forum Four: *"State of the States"*

July 22, 1997

Stephen A. Somers, Ph.D.
President
Center for Health Care Strategies, Inc.

Center for Health Care Strategies, Inc.

Affiliated with the Woodrow Wilson School of Public and International Affairs at Princeton University

The Center for Health Care Strategies, Inc., (CHCS) was established in 1995 as a non-profit, non-partisan policy and resource center affiliated with the Woodrow Wilson School of Public and International Affairs at Princeton University. CHCS serves as the National Program Office for two national initiatives of the Robert Wood Johnson Foundation (RWJF): the *Medicaid Managed Care Program* and the *Building Health Systems for People with Chronic Illnesses* program. CHCS has also received substantial funding from The Annie E. Casey Foundation to provide technical assistance and information through its *Children in Managed Care Initiative* and to help CHCS further develop its highly-rated Web site on health policy and managed care for vulnerable populations (http://www.chcs.org).

The *Medicaid Managed Care Program* is a $21 million national initiative. Its goal is to make managed care work for Medicaid recipients, especially those with chronic health conditions and social problems. Under this program, CHCS administers a competitive grant program with awards of up to $500,000 to states, managed care organizations, and others directly involved in making Medicaid managed care work. Thirty grants totaling more than $3 million have been made to date. CHCS also serves as a resource center to state and local governments, health care organizations, consumers, and the policy-making community on Medicaid managed care issues.

The *Building Health Systems for People with Chronic Illnesses* program has made grants totaling approximately $10 million over the last three years. A new $3 million Call for Proposals will be issued in September, 1997 for innovations in systems of care for people with chronic conditions, particularly children with special health care needs, individuals with physical disabilities, and those with mental illness.

The overall mission of CHCS is to promote the development and implementation of effective health and social policy for all Americans. In all of its work, CHCS places a high premium on finding practical solutions to current problems and promoting collaboration between the public and private entities responsible for making health care programs work for those most vulnerable to shifts in the political and fiscal environments. CHCS is staffed by individuals with a blend of experience from the health care industry, state and federal governments, philanthropy, and the consulting sector.

The CHCS board is chaired by Karen Hein, M.D., Executive Officer of the Institute of Medicine of the National Academy of Sciences. Dr. Hein is joined on the Board by Rhoda Karpatkin, J.D., President of Consumers Union; Leonard Lieberman, J.D., former Chairman of Supermarkets General Corporation; Frank McArdle, Ph.D., Principal of Hewitt Associates, LLC; Uwe E. Reinhardt, Ph.D., James Madison Professor of Political Economy, Princeton University; Michael Rothschild, Ph.D., Dean of the Woodrow Wilson School at Princeton; George Strait, ABC News Medical Correspondent; and Stephen A. Somers, Ph.D., President of the Center for Health Care Strategies, Inc. For more information on CHCS or its programs, please contact us via the numbers or addresses listed below.

7/97

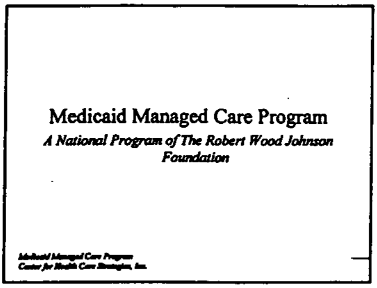
353 Nassau Street • Princeton, NJ 08540 • Phone: 609-279-0700 • Fax: 609-279-0956 • E-mail: mail@chcs.org

Forums on Managed Care for People with Special Needs

U.S. Senate Special Committee on Aging

Forum Four: "State of the States"

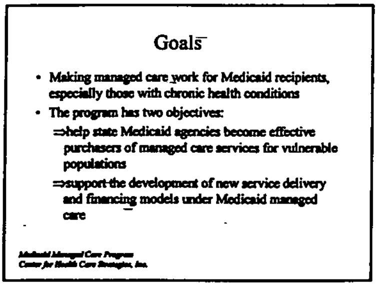
July 22, 1997



Medicaid Managed Care Program

A National Program of The Robert Wood Johnson Foundation

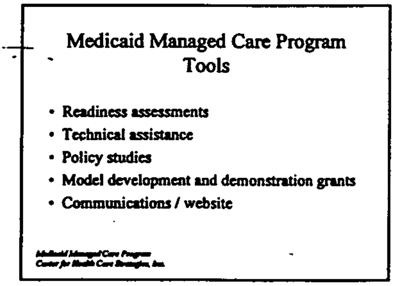
Medicaid Managed Care Program
Center for Health Care Strategies, Inc.



Goals

- Making managed care work for Medicaid recipients, especially those with chronic health conditions
- The program has two objectives:
  - ⇒help state Medicaid agencies become effective purchasers of managed care services for vulnerable populations
  - ⇒support the development of new service delivery and financing models under Medicaid managed care

Medicaid Managed Care Program
Center for Health Care Strategies, Inc.



Medicaid Managed Care Program Tools

- Readiness assessments
- Technical assistance
- Policy studies
- Model development and demonstration grants
- Communications / website

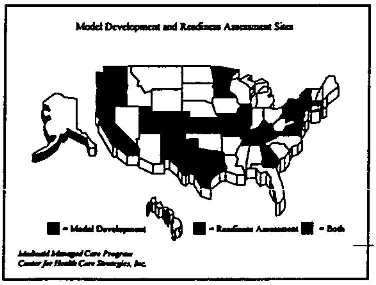
Medicaid Managed Care Program
Center for Health Care Strategies, Inc.

Forums on Managed Care for People with Special Needs

U.S. Senate Special Committee on Aging

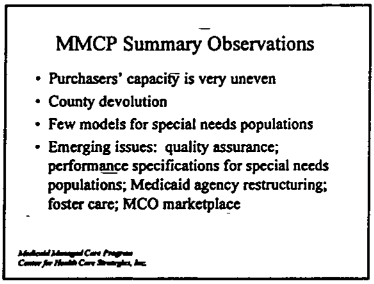
Forum Four: "State of the States"

July 22, 1997



Model Development and Readiness Assessment Sites

Medicaid Managed Care Program
Center for Health Care Strategies, Inc.

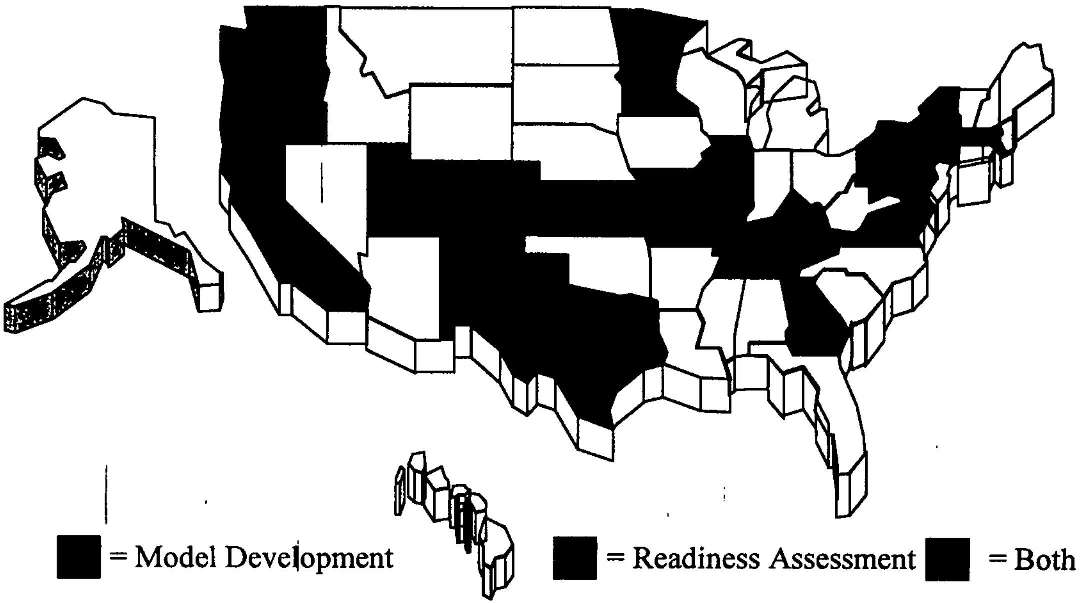


MMCP Summary Observations

- Purchasers' capacity is very uneven
- County devolution
- Few models for special needs populations
- Emerging issues: quality assurance; performance specifications for special needs populations; Medicaid agency restructuring; foster care; MCO marketplace

Medicaid Managed Care Program
Center for Health Care Strategies, Inc.

Model Development and Readiness Assessment Sites



Medicaid Managed Care Program
Center for Health Care Strategies, Inc.

Publications available

from the

Center for Health Care Strategies

Medicaid Carve-Outs: Policy and Programmatic Considerations (The MEDSTAT Group), March 1997 - $25.00

In Pursuit of Value: Innovative State/Medicaid Purchasing Strategies (C. Ginsberg), March 1997 - No charge

Medicaid Managed Care Contracting Guide (Medimetrix), July 1997 - $25.00

Colorado Access: Formation of a Medicaid Managed Care Plan (CO Access), July 1997 - $12.00

Quality in Managed Care for Persons with Developmental Disabilities (DDHA), July 1997- $12.00

Managed Care and Children with Special Health Care Needs: Consumer Leadership and Participation, (Family Voices/G. Bonnyman) August 1997 - $12.00

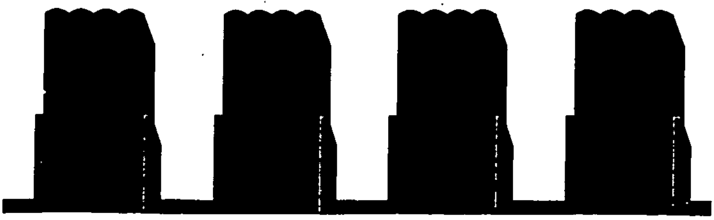
Functional Health Literacy: A Primer (Morley & Colello), August 1997 - $10.00

Medicaid Managed Care Rollovers (CO Access), August 1997 - $10.00

National Philanthropies' Medicaid-Related Grants (Morley), August 1997 - $10.00

Health Strategies Quarterly, CHCS Spring Newsletter - No charge

For publication ordering information contact Kamala Rickett, 609/279-0700.



Ms. CHRISTENSEN. Well, so much to absorb; I think I am going to just go sit at my desk and absorb it.

I know we are scheduled to leave at 11. For our panelists who are willing to stay and take questions, I believe the room is available, but if you have to leave, I don't have a problem with your leaving.

We can just go to questions unless anybody else wants to comment on anybody else's comments.

Any questions.

Yes.

QUESTION. [Inaudible.]

Ms. CHRISTENSEN. I'm sorry, I can't hear. If you want, we can put the mike out.

QUESTION. No. I can stand. [Inaudible.]

Ms. CHRISTENSEN. The question is: are many States including substance abuse in their Medicaid managed care.

Ms. SHIPNUCK. We are, and as I indicated, we have indicated that individuals who need substance abuse services are one of the special target special needs populations in Maryland.

The Maryland Medicaid package traditionally was not a generous one in terms of the fact that Medicaid did not cover residential treatment for adults, and when we started the program for the demonstration, we were bound by what had been in the package. What was very interesting was that as the legislature began to look at the tie-in with welfare reform, they determined that one of the barriers to employability was folks who had substance abuse problems.

So this year, before we even rolled out the demonstration, they expanded the substance abuse benefit package so that we have an enhanced benefit package. We have required managed care organizations to case-manage that, and we will be tracking that because the additional piece of it was not in our original capitation configuration. So we have some nuances to work with, but substance abuse is very much a specific service available to Medicaid recipients within Maryland.

Ms. HORVATH. I just looked at our June 1996 survey, which was a point-in-time survey, and we had asked how many States included substance abuse, and 28 said that they did for some or all of their enrolling populations. We asked how many are contracting with a separate risk contract—in other words it is pulled out of the general MCO contracting—where is a limited benefit in the general MCO contract or whether the full scope is covered. So States handle it different ways, but 28 said that in some way, shape or form, it is a capitated service.

Ms. BARTELS. I would add one other point. We also cover it in our managed care programs. Substance abuse treatment comes in many nontraditional models, and nontraditional models are not always covered by regular Medicaid fee-for-service; but in Medicaid managed care, with the appropriate contract requirements and incentives, managed care organizations will create those flexible and creative treatment alternatives, for example, that will create opportunities for moms and their kids to get the treatment they need without splitting up the family.

So I view Medicaid managed care as a great opportunity for substance abuse treatment to move forward in ways that many community-based organizations and treatment centers desire.

Ms. CHRISTENSEN. Yes?

QUESTION. [Inaudible.]

Ms. CHRISTENSEN. The question is about putting long-term care into a managed care system.

Ms. BARTELS. We released the proposal to integrate long-term care with what we call primary and acute health care in the State of Wisconsin, which would have been a very groundbreaking idea for elderly and disabled persons, and it was very, very threatening to the advocacy communities, managed care in general, and the whole concept of mixing medical with social services was threatening. In our State, so many of those services, as I alluded to in my testimony, are county-based. It created a real firestorm of controversy. Counties want to have the first right of refusal on being the managed care entities for this integrated program.

So we are seeking, through less organized, more intimate conversations with the interested parties, to see whether or not we can identify some areas of agreement before we proceed.

I think in general, it is a positive step, because people are talking about managed care being a positive thing for the elderly and disabled, but how to do it in a way that meets consumers' needs and does not upset the apple cart too much is a big challenge. But we are still committed to moving forward in that general direction. We have also been carving out long-term care from other health care services and trying to integrate health care services with the supportive social services that many disabled and elderly persons meet and desire.

Ms. CHRISTENSEN. Any other questions. [No response.]

Thank you so much. This has been incredible. We really appreciate your time and effort.

[Whereupon the forum was concluded.]

APPENDIX

PPRC

ual Report to Congress

1997

Physician Payment Review Commission

2120 L Street, NW, Suite 200, Washington, DC 20037
(202) 653-7220 fax (202) 653-7238
www.pprc.gov

Chapter 20

Medicaid: Spending Trends and the Move to Managed Care

Medicaid is an entitlement program providing payment for medical services to as many as 37 million low-income people who are aged, blind, disabled, or members of families with dependent children. It has three distinct features: joint federal-state financing, state administration in accordance with broad federal standards, and eligibility tied to standards for other cash benefits. Thus, although general eligibility and coverage standards are set at the federal level, each state designs and administers its own Medicaid program. As a result, state programs vary considerably in eligibility requirements, service coverage, utilization limits, provider payment policies, and use of managed care.

During the 104th Congress, both the Congress and the Administration proposed changes to the Medicaid program to limit growth in spending and permit more state innovation in service delivery and payment. Their proposals represented two general approaches to restructuring the Medicaid program: block grants and limits on per capita expenditures. Although both proposals provided more flexibility to states in running the Medicaid program, there were major differences. The congressional proposal would have made more substantial changes and deeper cuts than the Administration's, which retained more aspects of the current program. A later proposal made by the National Governors' Association adopted elements from both approaches. Although various versions of Medicaid legislation were passed by one or both houses of the Congress, no proposal became law. The enactment of welfare reform, however, does affect the Medicaid program. Because Medicaid eligibility historically has been linked to welfare eligibility, federal and state changes in welfare law may affect access to Medicaid benefits.

This chapter includes:

- *The financing and structure of the Medicaid program*
- *Medicaid spending trends*
- *Analysis of Medicaid managed-care enrollment*
- *Lessons from implementation of managed-care programs*

This chapter presents background information for understanding the policy debate that is likely to occur in the 105th Congress. It begins with an overview of the Medicaid program, including a brief review of the impact of welfare reform on the program. It presents trends in Medicaid spending, updating previous Physician Payment Review Commission reports that summarized spending by enrollment group, type of service, and state. This section also looks at evidence of a slowdown in Medicaid spending since 1992 and lower projections for future spending than those that drove policy debates in the last Congress.

The next section of the chapter focuses on Medicaid managed care. It first reviews state options for managed care, the waivers of federal rules that are needed to establish different programs, and the types of arrangements that states use. An analysis of how many beneficiaries are enrolled in managed care and how much of overall program spending goes to managed-care plans is then presented. This analysis is more difficult than it appears because of certain inconsistencies in the way beneficiaries and dollars are counted in Medicaid program data and in the different ways managed care is defined. Included in this analysis is the distribution of managed-care enrollment by state and by type of plan.

Finally, the chapter looks at the implementation of Medicaid managed care. The purpose of this section is to see what lessons can be learned from the experiences of the states—lessons that could be helpful to other Medicaid programs or to policymakers considering Medicare changes. Specific areas considered include restrictions on plan marketing, use of enrollment brokers, provision of information to beneficiaries, use of competitive bidding to select plans, and capitation payments to plans. This section concludes with suggestions for further research.

MEDICAID PROGRAM FEATURES AND EXPENDITURES

Much of the impetus for change in the Medicaid program has focused on rising federal and state expenditures. Although the rapid spending growth of the late 1980s has abated somewhat, spending is still projected to grow more quickly than the overall economy.

Financing

Medicaid is jointly funded by the states and the federal government.[1] The federal share of expenditures is determined by a formula based on state per capita income, under which states with relatively low per capita incomes receive higher federal matching rates. For example, Mississippi, with a per capita income that is less than 70 percent of the national average, had a matching rate of about 79 percent, while Connecticut, with a per capita income that is nearly 135 percent of the national average, received

---

[1] In addition to cited sources, the *Medicaid Source Book* was consulted for general information on the Medicaid program (CRS 1993).

a 50 percent match.[2] Since 1987, this matching rate has been recalculated annually. Overall, federal funds accounted for about 57 percent of total Medicaid spending in 1995.

Federal payments to the states are provided from general revenues to match expenditures submitted by the states. There is no limit on the total amount of federal payments. States may finance their share entirely from state funds or require local governments to finance up to 60 percent of program costs. Only a few states have exercised the latter option, with local sources accounting for a small proportion of state financing in most of these states.

Eligibility

Overall, Medicaid helps to finance health care for one of every eight Americans and about one-half of all Americans living in poverty. There is, however, no uniform national basis for establishing Medicaid eligibility. Within the limits of various federal rules, states may choose different eligibility criteria.

In general, beneficiaries can be grouped in three categories: adults and children in low-income families, blind and disabled individuals, and the elderly.[3] Within each category, people may qualify for coverage because they are either categorically or medically needy.

Under federal law, all people meeting 1996 standards for Aid to Families with Dependent Children (AFDC) and most on Supplemental Security Income (SSI) are considered categorically needy and are covered in all states. Starting in the mid-1980s, the Congress expanded Medicaid eligibility to include some persons who do not receive AFDC or SSI cash payments. For the most part, different income standards apply to each of three newly eligible groups: pregnant women and infants, children below the age of six, and children six and older. States have considerable flexibility in setting age and income thresholds (Liska et al. 1996). As a result of these expansions, the proportion of Medicaid beneficiaries who also receive cash welfare benefits declined from about two-thirds in 1990 to just over half in 1995 (CRS 1996).

States also may give Medicaid eligibility to the medically needy, those individuals whose income or resources exceed standards for cash assistance but who meet a separate state-determined income standard and are also aged, disabled, or a member of a family with dependent children. Persons who "spend down" income and assets due to large health expenses may qualify as medically needy. In 1996, 34 states extended eligibility to the medically needy (Liska et al. 1996).

Gap Between Eligibility and Enrollment. Some people who are eligible for Medicaid benefits do not sign up. According to the General Accounting Office (GAO), an estimated 3 million of the 14 million children who were eligible for Medicaid in 1994, based on federal standards for age and family income,

---

[2] The federal match for Medicaid services is legislatively set at a minimum of 50 percent and maximum of 83 percent.

[3] See Chapter 19 for a discussion of issues for beneficiaries dually eligible for Medicaid and Medicare.

were not enrolled in Medicaid or covered by private insurance. These Medicaid-eligible uninsured children accounted for 30 percent of all uninsured children in 1994 (GAO 1996a).

GAO indicates several reasons why a gap exists between eligibility and enrollment. First, some low-income families may not be aware that children can be eligible for Medicaid when a parent works full time or when two parents are present. Second, the enrollment process is difficult for low-income families. Some applicants never complete the process, and others are denied eligibility for procedural reasons that are correctable. In other cases, families may regard Medicaid as a welfare program and avoid enrollment unless faced with a medical crisis.

Some states operate outreach programs to get more children enrolled. States, however, face conflicting incentives. Although states seek to improve the health of their residents, expanded enrollment adds to the cost pressures that Medicaid places on state budgets. This is likely to be true even though new Medicaid spending may offset other state expenditures that directly or indirectly finance care for the medically indigent.

The Effect of Welfare Reform. Under federal welfare reform legislation (P.L. 104-193), states have the ability to unlink Medicaid eligibility from their new public assistance programs—while keeping a link to old AFDC eligibility standards. About 1.3 million children and more than 4 million parents receive Medicaid based solely on their eligibility for AFDC. Although the law eliminates the AFDC program and replaces it with a new block grant program called Temporary Assistance for Needy Families (TANF), those who were previously eligible for AFDC are supposed to retain Medicaid eligibility automatically. The new law permanently carries old AFDC rules and standards into the Medicaid program, rather than just grandfathering current beneficiaries' eligibility status. States are permitted to modify or simplify Medicaid eligibility standards as long as the 1996 Medicaid rules are treated as minimum standards. As a result of these changes, some individuals will now be eligible for Medicaid even though they are not eligible for TANF (HCFA 1996c; Center on Budget and Policy Priorities 1996; NHPF 1997).

By contrast, two other provisions of the new law may cause some people to lose Medicaid eligibility. First, tightened eligibility criteria for coverage of disabled children under SSI could lead some to lose Medicaid coverage. Some of these children, however, might qualify for Medicaid through other criteria (HCFA 1996b). Second, states will not receive federal matching funds for coverage provided to legal immigrants within five years of their entering the country. Legal immigrants already on Medicaid, however, will not lose their eligibility (HCFA 1996d).

Although the law makes only minor explicit changes in the Medicaid program, some analysts believe there may be greater indirect effects, ultimately reducing the numbers of people receiving Medicaid benefits. Even more than at present, some who qualify may not be enrolled because they do not understand that they are eligible or how to enroll. In addition, states will be faced with decisions on how simple to make Medicaid applications for those eligible for TANF and how aggressive to be in identifying people eligible for Medicaid but not for TANF (NHPF 1997).

If enrollment of eligible individuals does drop, one result may be that some of the poor may delay seeking Medicaid coverage until confronted with an acute episode, especially a costly inpatient stay. This situation is especially problematic if it means these individuals also defer preventive care because they lack coverage. Medicaid managed-care plans could be affected as well if delayed enrollment into Medicaid causes the mix of beneficiaries to be more expensive. States may base capitation rates on the lower utilization levels of the previous enrolled population. If so, plans drawing an average mix of enrollees would be more expensive than the healthier population on which capitation payments are based (United Hospital Fund 1996a; NHPF 1997).

As noted above, there is already a gap between eligibility and enrollment. The Commission last year reiterated its longstanding call for monitoring access in the Medicaid program (PPRC 1996). That recommendation called for the Department of Health and Human Services to monitor access and to report to the Congress on a yearly basis. As part of its recommendation, the Commission called for continued development of a uniform Medicaid claims and encounter data system, a requirement that states participate in that system, and development and administration of a periodic access survey of Medicaid beneficiaries and other low-income persons. The enactment of welfare reform heightens the urgency of monitoring access to health care and reemphasizes the need to determine whether there is an increase of eligible, but not enrolled, beneficiaries.

Spending by Enrollment Group

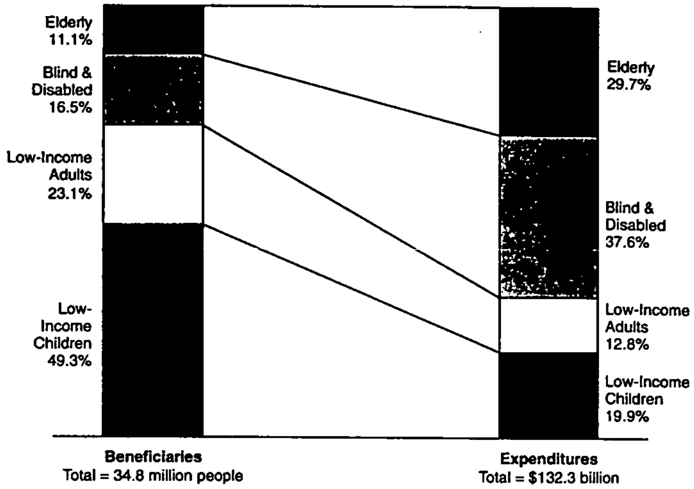
Patterns of service use and overall expenditures differ dramatically among the three major populations served by Medicaid (Figure 20-1). Children and adults in families with dependent children accounted for 72 percent of Medicaid beneficiaries in 1995, but only 33 percent of program payments.[4] By contrast, the elderly, only 11 percent of beneficiaries, accounted for 30 percent of total spending. Blind and disabled persons constituted 17 percent of beneficiaries and 38 percent of payments (Kaiser Commission 1996c; 1997a).

Viewed another way, Medicaid expenditures for each elderly beneficiary in 1995 were almost seven times those for each child and almost five times those for every adult in a low-income family (Figure 20-2). This difference is attributable largely, but not exclusively, to spending for long-term care for the elderly population; levels of acute spending are much more similar among these groups. Spending on blind and disabled beneficiaries is somewhat lower than that for elderly beneficiaries and includes a larger amount of acute care services than the other groups.

---

[4] This analysis excludes administrative expenses and payments to disproportionate share hospitals, which cannot be allocated by enrollment group.

Figure 20-1. **Medicaid Beneficiaries and Expenditures, by Enrollment Group, 1995 (percentage)**



SOURCE: Kaiser Commission on the Future of Medicaid 1997a.

NOTE: Total expenditures exclude administrative expenses and disproportionate share hospital payments.

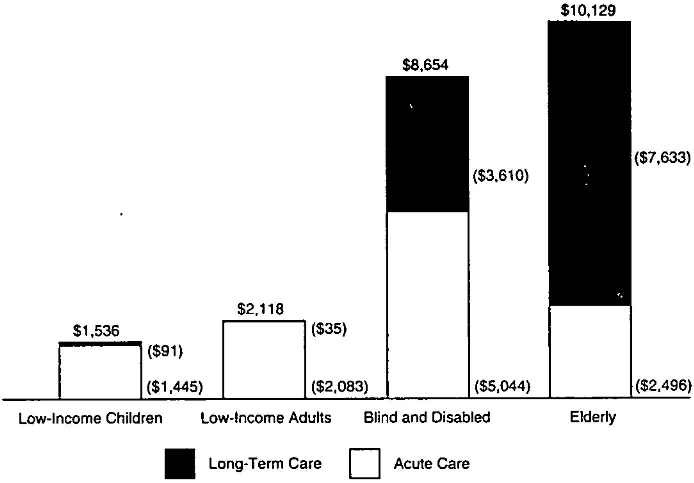
Spending by Service

Medicaid requires all states to provide categorically needy beneficiaries a standard benefit package that includes inpatient and outpatient hospital services; physician services; laboratory and X-ray services; family planning; skilled nursing facility (SNF) services for adults; home health care for persons entitled to SNF services; rural health clinic services; nurse-midwife services; and early and periodic screening, diagnosis, and treatment (EPSDT) for children.

The required benefit package for the medically needy is less comprehensive. States opting to cover the medically needy must, at a minimum, furnish ambulatory care for children and prenatal care and delivery services for pregnant women. Almost all states that have medically needy programs, however, provide the same services to both medically and categorically needy beneficiaries.

States may also provide (and receive federal matching payments for) other services, including prescription drugs; dental care; eyeglasses; services provided by optometrists, podiatrists, and chiropractors; intermediate care facility (ICF) services; and ICF services for the mentally retarded (ICF/MR). States vary considerably in the optional services they offer. Virtually all cover prescription drugs, ICF services, and optometrists' services. States must offer services uniformly throughout the state, providing comparable coverage to all categorically needy beneficiaries and allowing beneficiaries to obtain services from any qualified provider.

Figure 20-2. Medicaid Expenditures per Beneficiary, 1995 (dollars)



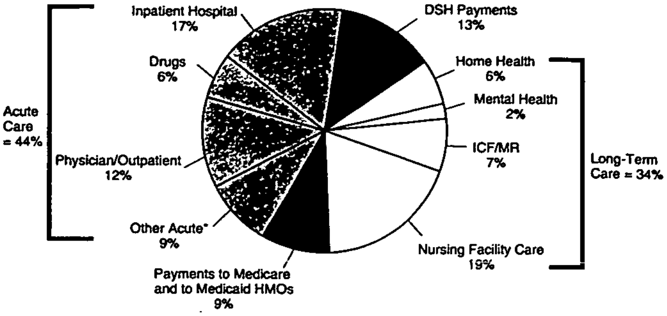
SOURCE: Kaiser Commission on the Future of Medicaid 1997b.

NOTE: Expenditures exclude disproportionate share hospital payments, adjustments, and administrative costs.

Several federal requirements establish Medicaid coverage for poor Medicare beneficiaries. Under these arrangements, beneficiaries typically receive help meeting Medicare cost sharing and may also be eligible for other benefits not covered by Medicare. Chapter 19 of this report provides a detailed examination of dually eligible beneficiaries.

It is not surprising, given the types of beneficiaries eligible for the program, that Medicaid spends large proportions of its budget on both acute and long-term care services (Figure 20-3). Overall, nursing facility care (for both mentally retarded and other beneficiaries) and inpatient hospital services accounted for the largest shares of Medicaid payments, about 26 percent and 17 percent of payments, respectively, in 1995 (Kaiser Commission 1996c; 1997a). Medicaid spends over one-third of its funds on long-term care services, a much higher share than for Medicare or national health spending as a

Figure 20-3. Medicaid Expenditures by Type of Service, 1995 (percentage)



SOURCE: Kaiser Commission on the Future of Medicaid 1997a.

* Includes case management, family planning, dental, EPSDT, vision, and other acute services.

NOTE: Total spending for 1995 was $151.8 billion.

whole.[5] In fact, Medicaid in 1994 funded almost half of all nursing home care in the United States (Levit et al. 1996).

Spending by State

Medicaid spending differs dramatically by state (Table 20-1). In 1994, the average annual payment per recipient of Medicaid services ranged from $2,261 in Tennessee and $2,529 in Mississippi to $10,036 in New Hampshire.[6] Because of the wide variation in states' proportions of their low-income populations participating in Medicaid, average spending per poor person ranged from $969 in Oklahoma to $4,874 in Connecticut. Finally, on a per capita basis, the highest spending occurs in New York ($1,164) and the District of Columbia ($1,350), the result of both high per beneficiary spending and large eligible populations (Liska et al. 1996).

While total state spending is a function of the actual number of Medicaid beneficiaries, differences in service coverage and payment policies also create spending differences across states. The pattern of Medicaid spending among service categories also varies by state. One state may put more money into long-term care, for example, while another state may emphasize inpatient hospital services.

---

[5] The proportion of Medicaid dollars spent on long-term care services has fallen, however, from nearly one-half in 1988 to about one-third in 1995 (Liska et al. 1996).

[6] New Hampshire's spending is about one-third higher than the next highest state ($7,311 in New York). The difference is New Hampshire's $4,596 per beneficiary in disproportionate share hospital payments. Its use of these payments is almost triple the next highest state (Liska et al. 1996).

Table 20-1. Medicaid Expenditures by State, 1994 (dollars)

	Total (millions)	Expenditures per		
		Capita	Poor Person	Medicaid Beneficiary
United States	$137,112	$ 523	$2,041	$4,011
Alabama	1,769	420	1,300	3,287
Alaska	288	500	2,083	4,181
Arizona	1,571	379	1,382	3,088
Arkansas	1,074	437	1,226	3,185
California	14,065	437	1,476	2,809
Colorado	1,119	306	1,602	3,904
Connecticut	2,424	744	4,874	7,042
Delaware	281	389	1,850	3,773
District of Columbia	790	1,350	3,530	6,214
Florida	5,347	372	1,225	3,096
Georgia	3,274	468	1,787	3,058
Hawaii	458	398	1,789	3,841
Idaho	312	264	1,069	2,833
Illinois	5,286	447	1,942	3,668
Indiana	2,811	483	2,085	4,676
Iowa	1,089	386	1,857	3,609
Kansas	981	390	1,798	3,897
Kentucky	1,867	493	1,579	3,007
Louisiana	4,065	949	2,593	5,368
Maine	932	729	2,689	5,288
Maryland	2,246	451	2,228	5,414
Massachusetts	4,696	779	4,254	6,672
Michigan	4,930	513	2,243	4,154
Minnesota	2,470	562	2,818	5,978
Mississippi	1,330	511	1,324	2,529
Missouri	2,533	483	1,685	3,788
Montana	344	398	1,513	3,627
Nebraska	615	372	1,984	3,867
Nevada	418	274	1,317	4,374
New Hampshire	830	726	4,472	10,036
New Jersey	4,793	598	3,256	6,152
New Mexico	665	400	1,249	2,581
New York	21,223	1,164	4,442	7,311
North Carolina	3,175	463	1,769	3,230
North Dakota	279	443	2,019	4,469
Ohio	5,499	486	2,174	3,676
Oklahoma	1,041	310	969	2,680
Oregon	1,105	354	1,531	2,686
Pennsylvania	6,432	531	2,496	5,123
Rhode Island	787	816	4,066	6,224
South Carolina	1,900	521	1,612	3,932
South Dakota	291	406	1,490	4,063
Tennessee	2,694	519	1,753	2,261
Texas	8,137	437	1,466	3,237
Utah	513	262	1,295	3,268
Vermont	284	479	2,442	3,088
Virginia	1,871	285	1,535	2,917
Washington	2,543	478	2,589	3,805
West Virginia	1,254	692	2,015	3,426
Wisconsin	2,256	445	2,133	4,797
Wyoming	158	323	1,355	3,186

SOURCE: Liska et al. 1996.

NOTES: Expenditures include disproportionate share hospital payments.

Beneficiaries are defined as individuals enrolled in the Medicaid program who actually receive medical services.

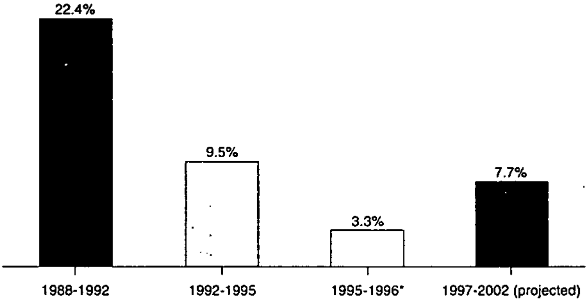
Poor defined as the number of individuals under 150 percent of the federal poverty threshold, which was $12,320 for a family of three in 1994.

Trends in Program Spending

In 1966, spending for Medicaid and its predecessor program accounted for $1.5 billion or 3.7 percent of the nation's personal health care expenditures. By 1994, Medicaid's spending (excluding administration) had increased to $122.9 billion and its share had climbed to 14.8 percent of personal health care expenditures (Lazenby et al. 1986; Levit et al. 1996). During this same period, the number of Medicaid beneficiaries grew from 12 million to 35 million (Kaiser Commission 1996b).

Medicaid spending growth has been quite volatile over the last decade. Spending went through a period of extremely rapid growth from 1988 to 1992 (Figure 20-4). The average annual growth rate over those years was 22.4 percent. From 1992 to 1995, spending growth declined to 9.5 percent (Holahan and Liska 1996). The current estimate of spending growth for 1996 is 3.3 percent (CBO 1997).

Figure 20-4. **Average Annual Medicaid Expenditure Growth Rate, 1988-2002** (percentage)



SOURCE: Holahan and Liska 1996; CBO 1997.

* Based on CBO estimate of spending.

The rapid growth from 1988 to 1992 was driven by three principal factors (Holahan et al. 1993; Holahan and Liska 1996). One was general health care inflation. A second was a significant expansion in enrollment due to both legislative changes and overall economic recession. During the 1980s, the Congress enacted a number of expansions in program eligibility—some mandatory and some optional. States responded by adding almost 8 million people to the Medicaid rolls, a one-third increase, from 1988 to 1992. A third factor was the use by many states of new financing practices, including provider taxes and donations and disproportionate share hospital (DSH) payments.[7]

---

[7] Disproportionate share hospital expenditures go to hospitals that serve a disproportionate number of low-income patients. States typically encouraged provider contributions or imposed taxes on providers. The state Medicaid program—with matching federal funds—would then increase payment to the hospital enough to return much or all of the donation or tax payment. In some cases, new funds were used to support care for the poor; more often, federal funds were substituted for state funds. DSH payments grew from $400 million in 1988 to more than $17 billion in 1992 (Holahan and Liska 1996).

The slowdown in spending after 1992 was equally dramatic and occurred in all categories of enrollees (Holahan and Liska 1996). At least three factors appear to have contributed to this trend. One is the limitation on the use of DSH payments as a result of 1991 federal legislation capping them (as well as restricting the use of other creative financing arrangements). After the rapid growth of earlier years, DSH payments rose by only 2 percent per year between 1992 and 1995.

A second factor was lower growth in spending per beneficiary. Although difficult to demonstrate, this change may be attributable in part to higher enrollment in managed care. Many states consider their managed-care initiatives central to reducing spending growth, but systematic evidence of savings remains unavailable. Managed care cannot be the only factor in moderating spending growth, especially since spending growth actually slowed more rapidly for elderly and disabled populations (who were not in managed care) than for low-income families (who were). General declines in medical price inflation, limits by some states on long-term care spending, and cost shifting to Medicare probably contributed to the slowdown.

A third factor was slower enrollment growth.[8] An improved economy was probably one factor in lowering the number of AFDC enrollees and thus lowering the number of Medicaid beneficiaries. Tightened eligibility requirements as part of state welfare reforms probably also contributed, as did the fact that congressionally driven expansions of eligibility were largely completed. In some cases, slower enrollment growth results from a trade-off made by policymakers—either an implicit or an explicit decision to forgo eligibility expansions in exchange for savings. For example, recent state requests for managed-care waivers have focused more on budget savings than on adding new populations. Similarly, policymakers may be deciding neither to target more age-income groups for eligibility nor to focus on outreach to enroll those who are eligible. As described above, policymakers may face even more difficult trade-offs as a result of welfare reform changes.

Projected Increases in Spending

Projections of spending increases have been a large factor driving legislative initiatives for Medicaid reform. Because new projections are lower than those of a year earlier, the pressure for changes has subsided somewhat. In January 1997, the Congressional Budget Office forecast an average annual rate of Medicaid spending growth of 7.7 percent for the period 1997 to 2002, a significantly lower estimate than those made earlier. In a separate analysis, Urban Institute researchers projected a growth rate of 7.5 percent. One contributing factor to these lower growth estimates is a revised assumption that enrollment growth will be between 1.3 percent and 1.5 percent, roughly half of previous projections. By contrast, enrollment growth was about 7.9 percent from 1988 to 1992 and 5.3 percent from 1992 to 1995 (CBO 1997; Holahan and Liska 1997; Kaiser Commission 1996b).

---

[8] Researchers at the Urban Institute and the Congressional Budget Office show slow enrollment growth (Holahan and Liska 1996; CBO 1997). By contrast, the Health Care Financing Administration's managed-care report shows a slight absolute decline in enrollment (HCFA 1997). As discussed later in the chapter, Medicaid data are often imprecise and unreliable.

MEDICAID MANAGED CARE

Most Medicaid services traditionally have been provided under fee-for-service arrangements. But the use of managed care has been rapidly expanding. In 1972, Medicaid had contracts with three plans: Health Insurance Plan of Greater New York, Kaiser Permanente in three states, and Group Health Cooperative of Puget Sound. By 1996, over 500 separate entities were serving beneficiaries. Managed care has accelerated in Medicaid during the last few years—from only about 282,000 beneficiaries in HMOs in 1981 to about 13 million beneficiaries in a variety of managed-care arrangements in 1996. After a brief overview of state options for implementing managed-care programs and the different organizational forms of managed care used within Medicaid, this section discusses different ways to measure the growth and penetration of managed care in Medicaid.

State Options and Waivers for Managed Care

Certain provisions of Medicaid law, such as the requirement that beneficiaries have the freedom to choose their providers, discourage the development of managed care. States may obtain waivers of Medicaid requirements from the Health Care Financing Administration (HCFA) to design programs without these constraints. Different types of Medicaid waivers vary in the amount of flexibility allowed and in the provisions of law to which they apply. The two types of waivers important for managed-care initiatives are program waivers under Section 1915(b) of the Social Security Act and demonstration waivers granted under Section 1115 of the Social Security Act. This section describes each of these.[9]

Section 1915(b) Program Waivers. Among other purposes, Section 1915(b) waivers permit states to mandate enrollment in managed care. HCFA can waive certain federal requirements (freedom of choice, uniform statewide operation, and comparability of benefits) to allow states to implement alternative health delivery systems or provider payment arrangements. To receive approval, a state must demonstrate that the program will be cost effective and that access to quality care will not be impaired. These waivers are granted for two years and can be renewed.

As of September 1995, 42 states and the District of Columbia had 1915(b) waivers for managed-care programs (Kaiser Commission 1996a). Michigan, for example, has waivers that allow it to limit Medicaid beneficiaries' choice of providers to primary care case management (PCCM) arrangements and health maintenance organizations (HMOs). Its PCCM program operates statewide, while HMOs are available only in selected counties. This combination is typical of many states.

---

[9] For a more extensive discussion of demonstration waivers, including those used for purposes other than managed care, see Chapter 8 of the Commission's *Annual Report to Congress 1995* (PPRC 1995).

Section 1115 Demonstration Waivers. Section 1115(a) of the Social Security Act allows the Secretary of Health and Human Services to approve demonstration projects that will help promote the goals of the Medicaid program. The Secretary has broad discretion in approving these demonstrations and has selectively approved such proposals. These demonstrations are for a limited time, usually three to five years. They generally have not been renewed by the Secretary, but the Congress has extended some legislatively.

The intent of Section 1115 demonstration authority is to test unique and innovative approaches to the delivery and financing of health care. Under a demonstration grant, the Secretary can waive many provisions of Medicaid law.[10] All other sections of the Medicaid law, except those explicitly waived, still apply to demonstrations. Demonstrations require research and evaluation components.[11] Although not a requirement in law, the Administration has a policy of only approving proposals that are budget neutral over the life of the demonstration.

In response to state officials' criticisms of the lack of flexibility in how Medicaid was run, the Administration has expanded use of this waiver authority. States use 1115 waivers to enroll Medicaid beneficiaries in prepaid managed care and to gain flexibility in meeting federal Medicaid program requirements. In addition, some states have sought to use 1115 waivers to expand Medicaid eligibility for acute care services to low-income, uninsured persons; but for the most part, pursuit of this goal has stalled.

As of December 1996, 17 states had been granted Section 1115 waivers. Two states have had their waivers denied. Montana's proposal was denied outright, while Louisiana's was turned down specifically because of the financing mechanism. Eight more states have applications awaiting decisions from HCFA (Kaiser Commission 1996c) (Figure 20-5).

Types of Managed-Care Arrangements

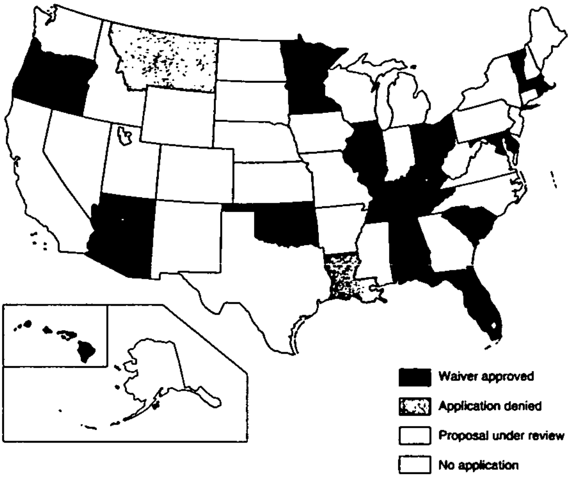
Medicaid managed-care arrangements vary widely in the amount of utilization management involved and the degree to which plans are at risk. HCFA classifies arrangements into four categories: HMOs, prepaid health plans (PHPs), health insuring organizations (HIOs), and PCCM arrangements. For most purposes, however, it is more useful to distinguish between entities at full risk for a comprehensive range of services (generally HMOs, HIOs, and some PHPs); entities at risk for a more limited range of services (some PHPs); and programs that operate on a fee-for-service basis (PCCM arrangements). The analysis presented in the next section makes use of this latter classification.

---

[10] One requirement that can be waived is the enrollment composition rule requiring that at least 25 percent of a plan's enrollees be from other than the Medicaid and Medicare programs. The Commission has previously recommended that this rule should be dropped for those states that participate in a quality assurance program (the Health Care Quality Improvement System) (PPRC 1993). See also Chapter 7 for a recommendation on Medicare's enrollment composition rule.

[11] Some evaluation research is under way. Early results from one study have been published (Wooldridge et al. 1997).

Figure 20-5. Status of Section 1115 State Medicaid Waivers, December 1996



SOURCE: Liska et al. 1996.

NOTE: Information has been updated to reflect approval of Alabama's waiver.

HMOs provide comprehensive health services to Medicaid beneficiaries in return for a capitated payment that is based on expenditures for comparable beneficiaries in fee-for-service Medicaid. Of the 511 entities participating in some type of Medicaid managed care in 1996, well over half (349) were HMOs.

Prepaid health plans have several variants. They include certain community, migrant, or Appalachian health centers located in medically underserved areas; organizations that contract with the state Medicaid agency for a specific list of services (e.g., behavioral health) or on a nonrisk basis; and comprehensive at-risk organizations that are statutorily exempt from HMO requirements. There were 89 PHPs contracting with Medicaid in 1996.

HIOs pay for services of subcontracting providers and plans and assume all financial risk in exchange for a premium. The HIO organizes a provider network and establishes preauthorization and utilization review to control the volume of services. Network providers serve as case managers and, in some HIOs, receive capitated payments. The extensive use of 1115 waivers has generally eliminated the need to use HIOs, although new ones have been authorized in California. There are only seven HIOs.

Primary care case management arrangements are different from HMOs, PHPs, and HIOs in that they operate on a fee-for service basis and are typically created and run by the states. Under these arrangements, a primary care physician coordinates and approves an array of services in addition to providing primary care services. In most PCCM systems, physicians are paid case-management fees (typically $3 per beneficiary per month) in addition to their regular fee-for-service payments for the primary care services they provide. In others, physicians are placed at financial risk for some services (usually ambulatory care). Physicians may determine the level of their Medicaid caseloads, up to a state-specified limit. PCCM arrangements operate in 31 states and the District of Columbia; a few states operate multiple programs.

Measuring Enrollment and Spending in Medicaid Managed Care

The Commission estimates that total Medicaid enrollment in all types of managed care in June 1996 was about 12.8 million, or 38.6 percent of all beneficiaries. There has been a steady growth in enrollment, resulting in more than a fourfold increase since 1991. In the last year alone, enrollment grew by one-third from 9.6 million beneficiaries (26.6 percent) in June 1995. Because managed-care enrollees are drawn disproportionately from low-income adults and children, the program's less costly populations, spending on Medicaid managed care represented only about 5 percent of total program spending in 1994. More recent spending data are not available.

Obtaining accurate counts for both enrollment and spending is not a simple task. The Commission's estimates of enrollment for 1995 and 1996 are lower than those published by the Health Care Financing Administration (HCFA 1996a; HCFA 1997). HCFA originally reported enrollment of 11.6 million Medicaid beneficiaries in 1995 and 13.3 million in 1996.[12] The principal reason for the differences between Commission and HCFA estimates is the inclusion or exclusion of different types of managed-care plans or arrangements.

Enrollment in plans that are at full risk for the cost of Medicaid services was about 8.8 million in 1996 (26.5 percent of all beneficiaries). These managed-care plans (generally all plans except PCCM arrangements) are more like those typically found in Medicare and the private sector. Growth in these types of plans has also been rapid—up 44 percent in one year.

Use of managed care by states varies considerably across the country. In five states (and Puerto Rico), more than three of four beneficiaries are in full-risk managed-care plans. At the same time, over one-third of the states have little or no enrollment, although many of these states run significant PCCM programs.

The following sections describe the Commission's analysis of managed-care enrollment and spending, aimed at deriving more accurate counts at both national and state levels. To some extent, this is an

---

[12] HCFA corrected its 1995 number in its report on 1996 enrollment issued in February 1997. The corrected estimate of 9.8 million is very similar—but not identical—to that derived by the Commission for this report.

exercise in purifying bad data. Although the numbers are important for policymakers who need to evaluate Medicaid trends, it is important to emphasize that better data are needed.[13]

Counting Enrollees in Managed Care. The goal of this section is to derive two sets of numbers for national and state level managed-care enrollment corresponding to two different criteria for including plans and arrangements. One is a count of Medicaid beneficiaries who participate in any kind of managed care for a broad range of health services. The second is a count of beneficiaries who enroll in an HMO or other health plan that is at full risk for a comprehensive range of services. In each case, managed-care carve-out arrangements that provide only dental or behavioral health services are excluded.

Excluding Carve-Out Plans. HCFA's annual reports on Medicaid managed-care enrollment have overcounted managed-care enrollment in significant ways (HCFA 1996a; 1997). An indicator of the problem was that HCFA's 1995 data showed six states (Colorado, Hawaii, Massachusetts, Oregon, Utah, and Washington) with more than 100 percent of their beneficiaries enrolled in managed care.[14] Calculated enrollment rates varied from 101 percent to 589 percent.

Dental and behavioral health managed-care plans provide substantially less than the full range of Medicaid services. For example, certain plans in 3 states provide only dental services, and plans in 11 states are restricted to behavioral health services (generally mental health and substance abuse).[15] These plans are sometimes referred to as carve-out plans. Some beneficiaries in these states enroll in both a regular managed-care plan and either a behavioral health plan or dental plan—and are thus counted twice. In fact, in some states enrollment in a fee-for service PCCM arrangement may automatically trigger enrollment in a risk-based behavioral health plan. Other beneficiaries may enroll only in these carve-out plans. Nationally, these two types of plans represent about 17 percent of HCFA's 1995 count of Medicaid managed-care enrollees (Table 20-2).[16] About 4 percent are in dental plans, and 13 percent are in behavioral health plans.

---

[13] In 1995, researchers at Lewin-VHI prepared an analysis of Medicaid managed-care enrollment. They collected enrollment numbers directly from state officials and compared them with HCFA's numbers. Their analysis shows that there may be even more inaccuracies than revealed by the Commission's analysis (Lewin-VHI 1995).

[14] A footnote on HCFA's enrollment tables suggested the problem, "Totals include duplicated counts of eligibles enrolled in multiple plans." In Hawaii, HCFA reported an additional data problem. Those enrolled under Hawaii's Section 1115 waiver are counted in the enrollment total, but not in the denominator (total recipients) (HCFA 1996a).

[15] In addition to the dental and behavioral health plans, there are plans in some states that provide only primary care services or an even more limited set of services, such as delivery and postpartum care only or newborn services only. They typically exclude hospital services, although they may require primary care physicians to review hospital admissions. These plans, however, appear not to duplicate coverage with other plans. They are not excluded from the Commission's counts, in part because they are not well-distinguished from some PCCM plans.

[16] Plans are identified, with enrollment counts, by HCFA (1996a). More detailed descriptions are in a report on plans operating under Section 1915(b) waivers (HCFA 1996e).

Table 20-2. Enrollment in Medicaid Managed Care, by Range of Services Covered, 1995

Range of Services	Number of Enrollees	Percent of Beneficiaries	Percent of Managed-Care Enrollees
Comprehensive Range of Services	9,640,309	26.6%	83.0%
Behavioral Health Services Only	1,535,780	4.2	13.2
Dental Services Only	443,840	1.2	3.8
Any Managed Care*	11,619,929	32.0	100.0

SOURCE: Physician Payment Review Commission analysis of Health Care Financing Administration data (HCFA 1996a).

* As noted by HCFA, this total includes duplicated counts of eligible beneficiaries enrolled in multiple plans.

The Commission has concluded that it is appropriate to eliminate enrollees in these carve-out plans from the managed-care counts. HCFA's solution, as shown in its most recent report, differs in that it attempts to eliminate only those enrollees who are double-counted (i.e., enrolled in both a carve-out plan and another managed-care plan) (HCFA 1997). The Commission's solution excludes carve-out plans that offer substantially less than the full range of Medicaid services. Adjustments have also been made to the 1994 and 1996 totals reported by HCFA using this approach.[17] These adjustments eliminate the double-counting of beneficiaries, reducing enrollment below 100 percent for five of the six states identified above (Table 20-3).

There are also errors in the counts of total beneficiaries, the denominators for these calculations, for several states. HCFA attempted to improve these data in its report on 1996 enrollment, noting that Medicaid population counts were collected by states at the same time the managed-care enrollment numbers were collected instead of using regular state data reports as in previous years.

An Accurate Count of Enrollment in Any Type of Managed Care. As previously noted, the Commission estimates that enrollment in any type of Medicaid managed care in 1996 was 12.8 million beneficiaries, accounting for 38.6 percent of all beneficiaries.[18] This estimate is about 500,000 below HCFA's published count. Total Commission-estimated managed-care enrollment in 1995 was 9.6 million. This count is about 2 million below the original count HCFA published and about 150,000

---

[17] HCFA's treatment of carve-out plans in 1994 was more consistent with the decisions described here. The 1994 data tables showed various plans with zero enrollees (HCFA 1995). Actual enrollments were shown in footnotes, but were not included in the totals. A few behavioral health plans in North Carolina and Washington, however, were not identified this way. Adjustments to the 1994 data are made to the tables reported later in this chapter. National enrollment is reduced by less than 1 percent; enrollment for Washington is reduced from 71 percent to 56 percent; enrollment in North Carolina is reduced from 20 percent to 9 percent.

[18] The National Academy for State Health Policy recently estimated enrollment in any type of managed care as between 12 million and 13 million beneficiaries. This estimate, which was based on decisions about carve-out plans similar to the Commission's, used data from a 1996 survey of the states (Horvath and Kaye 1997).

Table 20-3. **Enrollment in Medicaid Managed Care, with Adjustments for Dental and Behavioral Health Plans, 1995** (percentage)

State	Percent of Medicaid Beneficiaries Enrolled Before Adjustment	Percent of Medicaid Beneficiaries Enrolled After Adjustment
Hawaii	589%	298%*
Washington	141	58
Oregon	117	71
Colorado	114	47
Utah	102	55
Massachusetts	101	48
Iowa	86	31
North Carolina	30	18
California	23	21

SOURCE: Physician Payment Review Commission analysis of Health Care Financing Administration data (HCFA 1996a).

* Individuals who enrolled in managed-care plans under Hawaii's Section 1115 waiver are counted in enrollment totals, but not in the denominator (total recipients).

below its corrected figure. Even with these adjustments, the pattern of enrollment over a six-year period shows rapid growth, especially in the last two years (Figure 20-6).

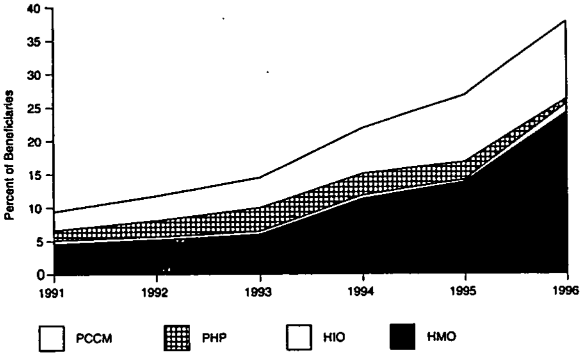
Medicaid managed-care enrollment is concentrated among low-income adults and children.[19] If viewed as a proportion of that population, the managed-care share would be about one-half in 1996. Putting Medicaid's managed-care penetration in context, the share of beneficiaries in managed care is roughly comparable to the proportion of workers in large firms who are enrolled in HMOs. But this share still lags behind the percentage of workers in any type of managed care.

Some 20 states, Puerto Rico, and the District of Columbia have more than 50 percent of beneficiaries in any type of managed-care arrangement (Figure 20-7 and Table 20-4). This figure is more than double the number of states at this level just one year earlier. These states include some (e.g., Arizona and Oregon), where high managed-care penetration characterizes the commercial market and others (e.g., North and South Dakota) that made policy decisions to move aggressively into Medicaid managed care in spite of a low commercial presence. At the other extreme, 8 states (down from 15 in 1995) have fewer than 10 percent of Medicaid beneficiaries in such arrangements. They are mostly small rural states (e.g., Mississippi and Vermont), but also include Texas.

---

[19] According to data from the National Academy for State Health Policy, just over one million elderly and disabled beneficiaries are in managed care (Horvath and Kaye 1997).

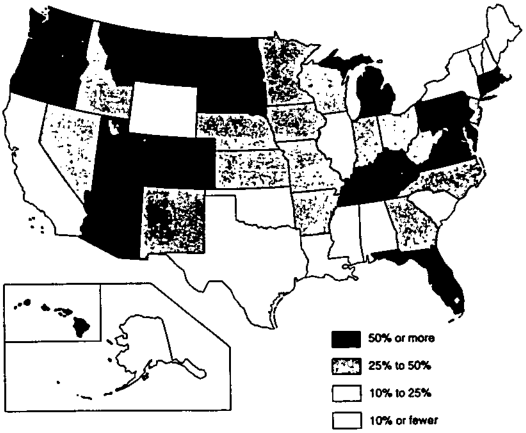
Figure 20-6. **Enrollment Growth in All Types of Medicaid Managed Care, 1991-1996**



SOURCE: Physician Payment Review Commission analysis of Health Care Financing Administration data (HCFA 1995; 1996a; 1997).

NOTE: Enrollment numbers are adjusted to exclude enrollees in dental and behavioral health plans.

Figure 20-7. **Enrollment in Any Type of Medicaid Managed Care, 1996**
(percentage of beneficiaries)



SOURCE: Physician Payment Review Commission analysis of Health Care Financing Administration data (HCFA 1997).

NOTE: Enrollment numbers are adjusted to exclude enrollees in dental and behavioral health plans.

Table 20-4. **Enrollment in Any Medicaid Managed-Care Plans, 1994-1996**
(percentage of beneficiaries)

State	1994	1995	1996
United States	21.5%	26.6%	38.6%
Alabama	6.8	7.3	11.4
Alaska	0.0	0.0	0.0
Arizona	69.1	68.3	86.1
Arkansas	22.8	38.8	38.6
California	16.3	20.6	23.1
Colorado	47.3	47.0	52.5
Connecticut	0.0	0.0	61.3
Delaware	3.5	8.4	77.6
District of Columbia	33.5	63.2	55.4
Florida	28.5	37.3	63.7
Georgia	0.2	12.2	32.0
Hawaii	4.1	*	80.4
Idaho	2.8	18.8	36.7
Illinois	11.1	9.2	12.9
Indiana	0.0	18.8	31.3
Iowa	15.4	30.5	41.4
Kansas	20.6	40.6	31.7
Kentucky	49.1	44.9	53.1
Louisiana	3.5	5.8	5.6
Maine	0.0	0.2	0.8
Maryland	75.4	77.3	63.5
Massachusetts	67.7	48.4	57.8
Michigan	34.8	64.6	72.7
Minnesota	28.2	29.7	33.2
Mississippi	6.1	6.0	6.9
Missouri	5.6	5.8	34.8
Montana	47.4	43.8	59.4
Nebraska	0.0	0.0	27.5
Nevada	23.8	34.0	40.9
New Hampshire	9.9	11.3	16.4
New Jersey	3.3	11.9	42.8
New Mexico	41.1	43.6	44.5
New York	11.4	19.8	23.5
North Carolina	9.2	17.9	32.3
North Dakota	46.9	46.6	54.6
Ohio	11.8	13.8	32.3
Oklahoma	0.0	0.0	19.4
Oregon	68.7	70.9	80.8
Pennsylvania	32.5	66.1	52.8
Puerto Rico	5.1	5.1	76.3
Rhode Island	1.6	44.7	62.7
South Carolina	2.6	3.2	0.6
South Dakota	4.3	28.1	64.5
Tennessee	90.8	54.8	100.0
Texas	2.6	2.5	3.8
Utah	60.0	54.8	78.0
Vermont	0.0	0.0	0.0
Virginia	30.6	43.2	67.8
Washington	55.9	58.0	60.5
West Virginia	23.5	24.6	30.4
Wisconsin	26.4	30.7	31.8
Wyoming	0.0	0.0	0.6

SOURCE: Physician Payment Review Commission analysis of Health Care Financing Administration data (HCFA 1995; 1996a; 1997).

* Individuals who enrolled in managed-care plans under Hawaii's Section 1115 waiver are counted in enrollment totals, but not in the denominator (total recipients).

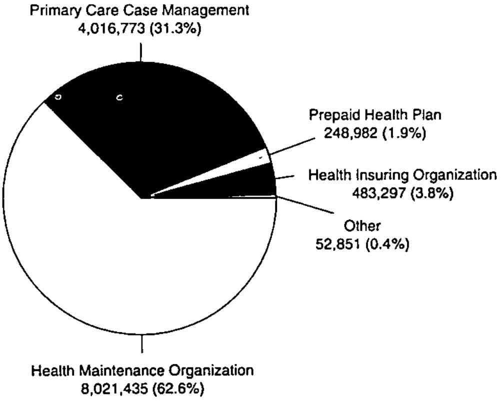
NOTE: Enrollment numbers are adjusted to exclude enrollees in dental and behavioral health plans.

Managed-care growth at the state level is uneven and highly dependent on the timing of waiver approvals and legislative decisions to proceed with new policies. Connecticut, for example, went from no enrollment to about 60 percent between 1995 to 1996. A few states saw modest decreases, but these may be partly a result of data inconsistencies.

An Accurate Count of Enrollment in Full-Risk Plans. Although the numbers cited above are accurate as estimates of participation in any type of managed care, they are not comparable to participation in the type of managed care that characterizes the Medicare program or most private-sector HMOs. As noted above, PCCM represents an approach to managing care, but without a transfer of financial risk to private plans or providers. Although physicians are paid a case-management fee, they bear no risk if utilization is high.

Using adjusted numbers, about 63 percent of all Medicaid managed-care enrollees are in HMOs, while about one-third (31 percent) are in PCCM arrangements (Figure 20-8). Only small numbers are in PHPs (2 percent), HIOs (4 percent), and other unclassified managed-care plans (less than 1 percent).[20]

Figure 20-8. Distribution of Medicaid Managed-Care Enrollment, by Type of Arrangement, 1996 (number and percentage)



SOURCE: Physician Payment Review Commission analysis of Health Care Financing Administration data (HCFA 1997).

NOTE: Enrollment numbers are adjusted to exclude enrollees in dental and behavioral health plans.

---

[20] Nearly all the excluded enrollees were in PHPs, which had closer to one-fourth of all enrollees in HCFA's reports.

Excluding PCCM participation reduces the enrollment in Medicaid managed care to 8.8 million beneficiaries, 26.5 percent of the Medicaid population.[21] The comparable figure in 1995 was 16.8 percent. Using this definition, Medicaid moved to about double the level of Medicare managed-care enrollment in 1996, after closely mirroring Medicare's enrollment level for the previous several years. Medicaid enrollment in full-risk plans is somewhat lower than the level of commercial enrollment in HMOs only and much lower than the level of enrollment in full-risk plans (see Chapter 1, Figure 1-14).

Like the national totals, state managed-care enrollment levels are affected by the inclusion of PCCM arrangements (Figure 20-9 and Table 20-5). There are 10 states—nearly all rural states in the South or Midwest—where PCCM is essentially the only type of managed care in use. In another 10 states and the District of Columbia, PCCM enrollment represents a substantial proportion of the managed-care involvement. With PCCM excluded, there are 9 states where managed-care enrollment exceeds 50 percent of the state's Medicaid beneficiaries. In 20 states, enrollment is below 10 percent.

Counting Spending on Managed Care. Although state Medicaid programs have enrolled a substantial portion of their beneficiaries in managed-care arrangements, the impact on Medicaid spending is far smaller. As noted previously, Medicaid spending is generated disproportionately by the two smaller segments of the beneficiary population: disabled and elderly beneficiaries. Because nearly all of the managed-care enrollment is drawn from children and adults in low-income families, it follows that the proportion of all Medicaid dollars that goes to HMOs is smaller than the proportion of beneficiaries enrolled.

According to 1994 data, HMOs received 5 percent of state and federal Medicaid dollars, while they enrolled 22 percent of beneficiaries that year.[22] Out of the spending on acute care services alone, nearly 10 percent went to HMOs. In only four states (Arizona, Florida, Oregon, and Tennessee) did managed care represent over 10 percent of all Medicaid dollars in 1994.[23]

Although this result is probably a rough indication of managed care's share of program dollars, the details may be somewhat unreliable or at least not fully comparable from state to state. Medicaid program spending data are collected and summarized by individual states and reported to HCFA. Although HCFA performs certain edits to improve consistency and accuracy and Urban Institute researchers have further refined the data, state reports frequently include both errors and inconsistencies.

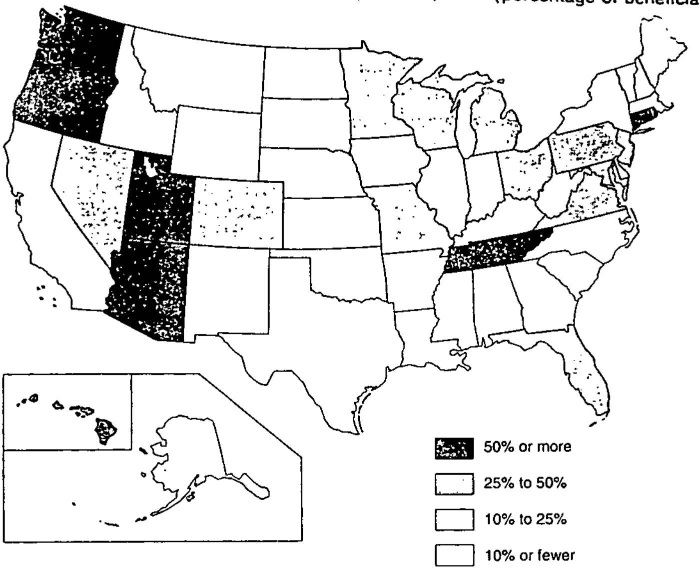
---

[21] There are about 230,000 enrollees in PHPs, HMOs, or other arrangements that are labeled as partial-risk arrangements in HCFA's database. They represent fewer than 1 percent of all Medicaid beneficiaries. Questions have been raised, however, about the accuracy of HCFA's classification of plans as partial-risk arrangements (Lewin-VHI 1995). To avoid basing adjustments on inaccurate data, these beneficiaries are left in the counts used in this chapter.

[22] The spending data analyzed here come from Urban Institute's analysis of 1994 data states reported to HCFA (Liska et al. 1996). Although HCFA has released more recent data, this analysis takes advantage of certain data cleaning performed by the Urban Institute researchers. As a result, 1994 data are the most recent available data that have been cleaned.

[23] Similar results are found in the analysis of Medicaid spending by Lewin-VHI (1995).

Figure 20-9. **Enrollment in Risk-Based Managed Care, 1996** (percentage of beneficiaries)



SOURCE: Physician Payment Review Commission analysis of Health Care Financing Administration data (HCFA 1997).

NOTE: Enrollment numbers are adjusted to enrollees in primary care case management arrangements and in dental and behavioral health plans.

Table 20-5. **Enrollment in Medicaid Risk-Based Managed-Care Plans, 1994-1996** (percentage of beneficiaries)

State	1994	1995	1996
United States	14.7%	16.8%	26.5%
Alabama	0.0	0.0	0.0
Alaska	0.0	0.0	0.0
Arizona	69.1	68.3	86.1
Arkansas	0.0	0.0	0.0
California	15.3	19.0	23.1
Colorado	8.0	13.7	27.5
Connecticut	0.0	0.0	61.3
Delaware	3.5	8.4	77.6
District of Columbia	12.6	34.0	30.1
Florida	20.5	24.9	25.4
Georgia	0.0	0.0	0.3
Hawaii	4.1	*	80.4
Idaho	0.0	0.0	0.0
Illinois	7.3	9.2	12.9
Indiana	0.0	6.3	11.8
Iowa	2.7	8.3	12.0
Kansas	0.0	0.0	4.4
Kentucky	0.0	0.0	0.0
Louisiana	0.0	0.0	0.0
Maine	0.0	0.0	0.0
Maryland	24.8	28.9	25.4
Massachusetts	16.6	11.8	13.3
Michigan	20.3	25.1	29.0
Minnesota	28.2	29.7	33.2
Mississippi	0.0	0.0	0.0
Missouri	4.6	4.6	33.7
Montana	0.0	0.0	0.8
Nebraska	0.0	0.0	15.3
Nevada	13.5	26.4	40.9
New Hampshire	9.9	11.3	16.4
New Jersey	3.3	11.9	42.8
New Mexico	0.0	0.0	0.0
New York	11.3	19.7	23.3
North Carolina	0.5	0.5	0.5
North Dakota	0.0	0.0	0.0
Ohio	11.8	13.8	32.3
Oklahoma	0.0	0.0	19.4
Oregon	67.8	68.0	80.8
Pennsylvania	27.8	37.9	32.0
Puerto Rico	5.1	5.1	76.3
Rhode Island	1.6	44.7	62.7
South Carolina	0.0	0.0	0.6
South Dakota	0.0	0.0	0.0
Tennessee	90.8	54.8	100.0
Texas	1.3	1.2	1.4
Utah	13.1	24.7	66.4
Vermont	0.0	0.0	0.0
Virginia	0.0	8.0	38.0
Washington	27.9	56.6	59.5
West Virginia	0.0	0.0	0.0
Wisconsin	26.4	30.7	30.3
Wyoming	0.0	0.0	0.6

SOURCE: Physician Payment Review Commission analysis of Health Care Financing Administration data (HCFA 1995; 1996a; 1997).

* Individuals who enrolled in managed-care plans under Hawaii's Section 1115 waiver are counted in enrollment totals, but not in the denominator (total recipients).

NOTE: Enrollment numbers are adjusted to exclude primary care case management arrangements and enrollees in dental and behavioral health plans.

The extent of problems in reporting managed-care spending data is suggested by calculations of spending per enrollee (Table 20-6). Among the states with at least 25 percent enrollment in all kinds of managed care in 1994, several spent close to the national average of $877 per enrollee. But others were well above that amount. Arizona's $2,515 per enrollee can be explained because Arizona funds its system primarily through capitation payments, including spending for the more expensive elderly and disabled beneficiaries (GAO 1995a). But other differences are harder to explain.[24]

Table 20-6. Medicaid Spending on Managed Care, for States with over 25 Percent Enrollment, 1994 (dollars)

State, by Proportion of Managed-Care Enrollment in Primary Care Case Management Arrangements	Spending on HMOs (thousands)	Spending Per Enrollee
United States	$6,803,637	$ 877
Over 75 Percent		
Kentucky	36	0
Montana	270	6
New Mexico	0	0
North Dakota	66	2
Virginia	15	0
25 Percent to 75 Percent		
Colorado	34,399	254
District of Columbia	37,661	884
Florida	544,374	1,106
Maryland	206,805	661
Massachusetts	347,622	729
Michigan	401,933	973
Pennsylvania	577,354	1,417
Utah	25,308	269
Less than 25 Percent		
Arizona	884,459	2,515
Minnesota	175,386	1,505
Oregon	164,670	583
Tennessee	896,972	829
Washington	204,556	548
Wisconsin	186,959	1,504

SOURCE: Physician Payment Review Commission analysis of data from HCFA (1995) and Liska et al. (1996).

NOTE: In calculating spending per enrollee, enrollees in dental and behavioral health plans were excluded.

---

[24] Two states, not shown in Table 20-6, are particular anomalies. Hawaii's estimated spending of $8,676 per enrollee probably results from inaccurate counting of managed-care enrollment. Indiana reported $223 million spent on HMOs but no managed-care enrollees. Indiana did report substantial managed-care enrollment in 1995, so the error could be a discrepancy in the timing of reporting of different types of data.

Several states reported annual spending per enrollee of $100 or less, including some that showed no spending on HMOs. The vast majority of these states' managed-care programs were organized on the fee-for-service PCCM model in 1994. Apparently they report only the case-management fees paid to physicians as managed-care expenses—if they even report those. Other services are presumably accounted for on a fee-for-service basis.

If all fee-for-service PCCM enrollment is eliminated from the accounting, managed-care spending per enrollee is estimated at about $1,200, far lower than Medicaid's overall 1994 level of about $4,000 spending per beneficiary (Table 20-1). But because most managed-care enrollees are not from the higher-spending groups in the program (the elderly or disabled), the average 1994 spending of $1,550 per beneficiary among low-income adults and children would be a better comparison. The difference between this $1,550 average and the $1,200 average for those enrolled in managed care could reflect savings accomplished in managed care. It could also reflect factors such as risk selection or differences in average spending or benefits covered between states with low and high managed-care penetration.

The Bottom Line on Counting Managed-Care Enrollment and Spending. The Commission's analysis leads to two conclusions about managed-care enrollment and spending. First, using available data, it is possible to estimate the levels of enrollment in any Medicaid managed care and in full-risk managed-care plans. Very rough estimates of spending in the typical Medicaid managed-care program have also been made. These estimates are important for understanding the dimensions of the role managed care is playing in Medicaid.

More importantly, however, the data are extremely unreliable, so that the estimates reported here are quite approximate. If the role of managed care in Medicaid is to be understood fully, better data should become a priority for the program.

IMPLEMENTATION OF MEDICAID MANAGED CARE

States that have moved actively into Medicaid managed care have made a number of different decisions about how to structure program features such as enrollment and disenrollment, marketing, use of enrollment brokers, selection of plans, and capitation payments to plans. Examination of these decisions is important for at least two reasons. First, as more states opt to move more Medicaid beneficiaries into managed care, they will face a similar set of decisions. It would be helpful if these states could avoid repeating mistakes made by their predecessors.

Second, the Medicaid experience may offer lessons for the Medicare program. If future changes in Medicare should call for a rapid expansion of managed-care enrollment, then the Medicaid experience could be instructive, especially to the extent that both programs have sizeable populations with no managed-care experience. In some cases, the Medicaid experience appears to reinforce previous Commission conclusions about policies for Medicare, for example, that the availability of comparative information on plan options is critical for beneficiaries to make meaningful choices among competing plans (PPRC 1996). In other areas, the Medicaid experience may offer insight into issues, such as the use of enrollment brokers, where the Medicare program lacks experience.

Studies of state experience in Medicaid managed care by three organizations provide material for this section. The final part of this section describes further work needed to study relevant policy issues more fully.

First, the National Academy for State Health Policy (NASHP) recently published its third survey of state Medicaid programs, conducted in 1996 (Horvath and Kaye 1997). It included separate analyses of risk-based programs (found in 38 states) and PCCM arrangements (32 states). Like earlier surveys, it covers several topics of interest to the Commission. NASHP also completed a study of state enrollment and disenrollment policies in 1996 (Horvath and Kaye 1996).

Second, the Commonwealth Fund and the Henry J. Kaiser Family Foundation funded a series of case studies examining the experiences of five states (California, Minnesota, New York, Oregon, and Tennessee) in implementing managed-care initiatives (Gold et al. 1996).[25] These studies involved site visits to the states in 1994 and 1995 to identify issues and early lessons. Each of the studied states had set a goal of moving at least half of its beneficiaries into managed care—some within a year's time, others over a longer period. Two states were operating under approved Section 1115 waivers; two others had initiatives under way, while awaiting approval of Section 1115 waiver applications. The fifth was operating under a Section 1915(b) waiver.

Finally, the General Accounting Office in 1996 released a report on Medicaid managed care (GAO 1996b). It reviewed documented cases of marketing and enrollment abuses from five states (California, Florida, Maryland, New York, and Tennessee) that had received media attention for their problems. It also studied education and enrollment programs in four states (Minnesota, Missouri, Ohio, and Washington) that were identified by experts as noteworthy for their innovative approaches. In addition, GAO has made several other reports to the Congress on individual state experiences in Medicaid managed care (GAO 1995a; 1995b).

Restrictions on Plan Marketing

States have the option of relying on participating health plans to market their products to beneficiaries. But states may also ban direct plan marketing and take responsibility themselves for informing beneficiaries about their options. The case studies found significant problems resulting from direct plan marketing, leading a number of states to assume the marketing function.

---

[25] Individual case studies have been published for the five states (Gold et al. 1995a; 1995b; Sparer and Chu 1996; Sparer et al. 1996a; 1996b). Site visits, as part of this study, have been made to two additional states, Florida and Texas. The Florida case study is complete and will be released shortly; the Texas case study is in preparation.

For states relying on plans for marketing, HCFA has guidelines that most have adopted. The guidelines require plans to demonstrate that their marketing materials are accurate and that procedures used do not mislead or confuse beneficiaries. Plans appear to prefer direct marketing because it enhances their ability to increase market share. Plans also find that they are able to combine marketing with other tasks, such as orientation of new enrollees. Typically, direct marketing occurs at beneficiaries' homes, in public assistance offices, at community sites like check-cashing locations, or through targeted mass mailings. Plans are permitted to offer gifts (with a value under $10) as incentives to enroll (GAO 1996b).

According to the 1996 NASHP survey, only 10 states operating risk-contracting programs relied solely on government for outreach and marketing, and only 1 state gave plans sole responsibility. Most shared responsibility in some way (Horvath and Kaye 1997).

The 1996 GAO study cited various reported abuses that have resulted from plans' marketing activities. Examples included misrepresentations by plans' sales agents to beneficiaries, especially about the use of network providers; inappropriate or fraudulent enrollment by sales agents who are paid on commission for each person enrolled; and abuses of gifts used as enrollment incentives. Each of the five states where abuse had been reported took enforcement actions or levied fines against the offending health plans. In addition, four banned or restricted door-to-door marketing by plans. New York, however, temporarily suspended its ban because it led to a decline in enrollment (GAO 1996b).

The four states that GAO identified as examples of innovative programs all prohibited or significantly restricted plans from initiating contact with nonenrolled beneficiaries. These decisions generally came in conjunction with the states' moves to mandatory enrollment. These states either chose to act directly as the principal source of information or to employ enrollment brokers.

GAO concluded from its study that allowing plans to market directly to Medicaid beneficiaries resulted in some abusive practices that states find difficult to prevent. While the agency found that performance measures are needed to determine what approaches to education and enrollment work best, it appeared to prefer that these efforts be organized by the state (directly or through brokers).

Of the five states in the Kaiser/Commonwealth study, two have banned direct plan marketing altogether. The other states have allowed at least some marketing by plans. As in the GAO study, the researchers reported that enrollment and marketing processes functioned much more smoothly where plan marketing was prohibited than elsewhere. The study pointed out that the design and funding of these processes is critical and that problems arise even with good planning. Oregon, for example, initially received 4,000 calls a day—compared with expectations of 5,000 calls per month (Gold et al. 1996).

One concern raised in states where plan marketing was not permitted came from smaller Medicaid-only plans. They thought they were placed at a competitive disadvantage because they could not build name recognition through advertising nominally directed to the commercial market.

There appears to be a clear trend for states to regulate plan marketing tightly or, in many cases, to ban direct plan marketing. This trend has created new interest in finding other ways to inform beneficiaries about their options.

Enrollment Brokers

A growing number of states have chosen to contract out education and enrollment responsibilities to enrollment brokers. GAO reported that, overall, more than half of the states with a mandatory managed-care program use enrollment brokers or are considering contracting with them (GAO 1996b). The 1996 NASHP survey identified 18 states that used a private entity (other than the plans) for marketing their risk-based plans, though not all used them as the sole source of information. Other states use brokers in their PCCM programs (Horvath and Kaye 1997).

Conclusions about the effectiveness of using private enrollment brokers are mixed. Generally, the fact that enrollment counseling is done at all appears to be more important than whether the state contracts the function out to a private entity. NASHP concluded that benefits counseling can be contracted out to a private entity or performed by agency caseworkers, but that the most significant factor is the scope of responsibilities assigned to the benefits counselor (Horvath and Kaye 1995).

One indicator used to evaluate the effectiveness of different enrollment approaches is the extent to which beneficiaries choose their own plan or whether the state (assuming a mandatory enrollment policy) assigns them to one of the available plans. A well-designed enrollment counseling program, concluded NASHP, should help reduce the number of state assignments, boost satisfaction with choices of plan and providers, and lead to greater acceptance of managed care generally (Horvath and Kaye 1995).

The Kaiser/Commonwealth study reached a mixed conclusion about using enrollment brokers. In two of five states, the study reported that the enrollment experience was smooth. Oregon used an enrollment broker, while Minnesota handled the task through the state and counties. By contrast, the study found that in California, where a broker was used in the Sacramento County program, enrollment was characterized by confusion. Because the county preferred running the program itself, the state's decision to award the contract to a private broker was controversial and was finalized only four months before mandatory enrollment was to begin. The resulting process was characterized as chaotic and problematic, with incomplete informational materials, an understaffed toll-free telephone line, and other problems. About 16 percent of beneficiaries signed up for more than one plan. Some of the problems were resolved only after a 90-day delay of the program's start-up, but other problems have persisted (Gold et al. 1996; Sparer et al. 1996b).

GAO reported that using state employees as enrollment counselors can take advantage of in-house knowledge of the Medicaid program and the populations served. At least in the short term, though, it may be hard to add enrollment and education responsibilities to staffers' existing obligations for the fee-for-service program. Enrollment brokers can sometimes develop needed services (including services for non-English-speaking beneficiaries and toll-free telephone lines) at a lower cost than the state can. Missouri reportedly chose to use a broker because of limits it faced in hiring more state employees and because it could accelerate implementation with this approach. Ohio, on the other hand, chose this approach because of a good experience in Dayton, where use of brokers provided a neutral source of information (GAO 1996b).

Availability of Information

As noted above, beneficiary education and counseling can be critical to the success of managed-care initiatives. Although none of the studies reviewed here had data from beneficiaries to judge how well-informed or satisfied they were with the enrollment process, they agreed on the importance of the information process. Furthermore, they agreed that the content of the information and the process by which it is communicated are critical. The source of information is less vital, provided it is neutral and unbiased.

GAO's report noted that all four states selected for their exemplary programs took responsibility in some way for the task of informing beneficiaries about how best to access care in a managed-care system and how to choose a plan. These tasks are particularly important for a clientele having only limited experience with managed care or its restrictions on provider use (GAO 1996b).

States chose to use in-person meetings and mail or telephone contacts, depending on available resources and how rapidly decisions had to be made. GAO concluded that states seemed to prefer in-person interactions where possible. Whether these sessions occur in small groups or as individual interactions, they give counselors a chance to explain complex materials and choices. States that use mail or telephone contacts may use in-person consultations as a backup. All four states studied also used community-based groups to supplement the state's educational programs. The GAO study did not, however, report in detail on the content or subject matter of informational materials or meetings (GAO 1996b).

The Kaiser/Commonwealth study pointed to similar findings in drawing lessons from the five state experiences. For example, it cited the importance of an enrollment process that includes written materials designed for low-income populations, a toll-free telephone number that can address a large volume of questions, and a means of providing in-person counseling (Gold et al. 1996).

There are many issues related to the content of the information provided. Beyond factual data on plan characteristics that beneficiaries need to make choices, good information about provider networks is also needed. In addition, experts cite the importance of performance data, including the use of Medicaid's edition of the Health Plan Employer Data and Information Set (HEDIS). According to the NASHP survey, 27 states used some version of HEDIS. Only two, however, used reports cards as an educational strategy (Horvath and Kaye 1997). Many of these issues parallel similar issues that the Commission has addressed for the Medicare program (see Chapter 7).

Enrollment and Disenrollment Policies

Medicaid law requires that beneficiaries retain full freedom of choice of providers. As a result, mandatory enrollment in HMOs requires a waiver. Further, Medicaid law generally limits enrollment lock-ins to one month, although a six-month lock-in is allowed for an HMO meeting certain federal requirements. Under a Section 1115 waiver, lock-ins may be extended to 12 months. Where mandatory enrollment is in place, states must also determine whether to establish an annual open enrollment season or to allow continuous enrollment. These policies can become especially complex for Medicaid, where beneficiaries can gain and lose eligibility for benefits multiple times during a year.

A majority of states now have some type of mandatory enrollment policies, although details vary considerably. According to the NASHP survey, 31 of 38 states with risk-based programs have mandatory enrollment. Those not choosing a plan are assigned one. Most states with PCCM programs also have mandatory enrollment. Apparently, most states have maintained the monthly right to disenroll. Nine states, however, reported using a six-month lock-in, and five (all Section 1115 waiver states) set a 12-month lock-in period (Horvath and Kaye 1997).

NASHP, however, found no connection between different enrollment policies and rates of disenrollment or auto-assignment. It also found little use of disenrollment data as a program management tool (Horvath and Kaye 1996). None of the studies, however, drew conclusions about the broader effects of extending lock-ins beyond requirements in current law.

Competitive Selection of Plans

The use of competitive bidding to select plans for participation in managed-care programs is a significant trend in Medicaid, with eight states now using it in some way (Horvath and Kaye 1997). Arizona has used this approach for more than a decade, and it has been credited with helping to keep costs down (GAO 1995a). In several other states, the use of competitive bidding is much more recent. It is probably too early, therefore, to draw any conclusions. Competitive bidding is thus an ideal candidate for further research.

In 1994, Arizona sought bids for three-year contracts with plans. The state described its general requirements in a request for proposals and received 95 bids for 42 contracts it was making available in 15 counties. Arizona had previously developed capitation rate ranges based on historical utilization data. These ranges, not shared with the bidders, were used to evaluate the bids. Low bids received higher scores, but bids that were excessively below the range were considered unacceptable. If an initial bid was above the range, the bidder was allowed to submit a second bid. Arizona also evaluated a plan's provider network, its management, and its past experience. Ultimately, the 42 contracts were awarded to 14 plans (GAO 1995a).

California is implementing a new system for selecting plans in 12 of its largest counties. In each case, two plans are permitted to enroll beneficiaries. One is called a local initiative plan and is normally formed by the county government. This option was designed in part to protect county-based safety net providers. The other, called a mainstream plan, is a private plan selected through a bidding process. Apart from the mechanics of the bidding process, this approach has been criticized by the managed-care industry for unnecessarily limiting competition and beneficiary choice.[26] In some counties, lawsuits have been filed challenging the selection process. Implementation was also delayed until the 1915(b) waiver was approved and because of start-up problems with the local initiative plans. Although mainstream plans were chosen in most counties in 1995, the two-plan model is not yet operational in any county (GAO 1995b; Sparer et al. 1996b).

New York State adopted competitive bidding in 1995. New York City recently awarded contracts to 20 plans, 6 of which were new to the program. Plans that met the state's initial technical and financial criteria were reviewed by city officials before being offered contracts. Although some plans were not approved, the plans whose contracts were renewed accounted for 97 percent of previous enrollment (United Hospital Fund 1996b).

Capitation Payments and Risk Adjustment

According to the NASHP survey, 30 of 38 states with risk-based programs used a rate-setting approach to establish capitation payments (Horvath and Kaye 1997). Many of these are similar to that used in the Medicare program. States tell plans how much they will pay to provide services to plan enrollees. By law, capitation payments to managed-care organizations must be computed on an actuarially sound basis and cannot exceed what would be paid for an equivalent group under fee-for-service Medicaid. The latter requirement has been waived in some demonstration states.

States typically pay a percentage (generally 85 percent to 95 percent) of the cost of serving enrollees under fee-for-service Medicaid.[27] This approach is designed to guarantee a level of savings to the states. As in Medicare, savings may not be realized if risk differences between plan enrollees and other beneficiaries are not accounted for through a risk-adjustment mechanism. In states with mandatory enrollment (at least for certain categories of beneficiaries), risk adjustment is not a problem for guaranteeing savings to the state, although it may be an issue in ensuring fair payment among participating plans.[28]

One issue is whether the methods used provide compensation that is adequate to support access for beneficiaries and to encourage competition among plans. The Kaiser/Commonwealth study found that three of five states set uniform rates for all plans in a given area, while the other two negotiated

---

[26] In some cases, the local initiative plan can contract with a number of private health plans, resulting in more choice for beneficiaries than appears on the surface.

[27] Even more than in Medicare, this calculation is increasingly problematic. As the proportion of beneficiaries in managed care grows, the cost experience of fee-for-service beneficiaries becomes a less stable and less typical basis for calculating capitation rates.

[28] See Chapter 5 of this report for a discussion—mostly in the Medicare context—of the importance of risk adjustment for promoting access to care for vulnerable populations.

individually with plans over rates (within constraints) (Gold et al. 1996). In several states, notably Tennessee, the level of the capitation rates has been a central issue in debates over the program's future. Several managed-care plans withdrew from state programs in 1996, blaming state cuts in payments among other factors (Page 1997).

An additional issue is whether states are making progress in developing and implementing innovative approaches to risk adjustment. The NASHP survey found that a majority of states make risk adjustments for age, sex, geography, and eligibility category. Most states also used some type of risk sharing or reinsurance. Only four reported adjusting rates for health status in 1996 (Horvath and Kaye 1997).

Further Research

States' experiences in implementing their managed-care programs may be instructive both to other states' Medicaid programs and to the Medicare program. With the variety of approaches in use, several natural experiments are under way. Although the studies identified here offer some suggestions about what approaches have been more successful than others, more systematic research on these issues is needed. Some studies are in progress, including ongoing survey work by the National Academy for State Health Policy and projects funded by HCFA and by the Robert Wood Johnson Foundation.

The first stage in a study to examine these issues further would be a survey of states with significant managed-care activity. The survey should cover some of the topics identified in this section. For example, it might ask about restrictions states place on plan marketing, use of enrollment brokers, how information is communicated to beneficiaries, use of competitive bidding to select plans, setting of capitation payments, and risk adjustment. A second stage could explore the success and failure of these different approaches and some of the factors that help determine which succeed and which fail.

REFERENCES

Center for Budget and Policy Priorities, "An Analysis of the AFDC-Related Medicaid Provisions in the New Welfare Law," unpublished memorandum, September 19, 1996.

Congressional Budget Office, *The Economic and Budget Outlook: Fiscal Years 1998-2007* (Washington, DC: January 1997).

Congressional Research Service, *Medicaid Source Book: Background Data and Analysis (A 1993 Update)*, Committee Print 103-A (Washington, DC: Committee on Energy and Commerce, U.S. House of Representatives, January 1993).

Congressional Research Service, *Medicaid Spending and Enrollment: A State Chart Book*, No. 96-839 EPW (Washington, DC: October 10, 1996).

General Accounting Office, *Arizona Medicaid: Competition Among Managed Care Plans Lowers Program Costs*, GAO/HEHS-96-2 (Washington, DC: October 1995a).

General Accounting Office, *Medicaid Managed Care: More Competition and Oversight Would Improve California's Expansion Plan*, GAO/HEHS-95-87 (Washington, DC: April 1995b).

General Accounting Office, *Health Insurance for Children: Private Insurance Coverage Continues to Deteriorate*, GAO/HEHS96-129 (Washington, DC: June 1996a).

General Accounting Office, *Medicaid: States' Efforts to Educate and Enroll Beneficiaries in Managed Care*, GAO/HEHS-96-184 (Washington, DC: September 1996b).

Gold, Marsha, Karyen Chu, and Barbara Lyons, *Managed Care and Low-Income Populations: A Case Study of Managed Care in Oregon* (Menlo Park, CA: Henry J. Kaiser Family Foundation, July 1995a).

Gold, Marsha, Hilary Frazer, and Cathy Schoen, *Managed Care and Low-Income Populations: A Case Study of Managed Care in Tennessee* (Menlo Park, CA: Henry J. Kaiser Family Foundation, July 1995b).

Gold, Marsha, Michael Sparer, and Karyen Chu, "Medicaid Managed Care: Lessons from Five States," *Health Affairs* 15(3):153-166, Fall 1996.

Health Care Financing Administration, Department of Health and Human Services, *Medicaid Managed Care Enrollment Report: Summary Statistics as of June 30, 1994* (Baltimore: 1995).

Health Care Financing Administration, Department of Health and Human Services, *Medicaid Managed Care Enrollment Report: Summary Statistics as of June 30, 1995* (Baltimore: 1996a).

Health Care Financing Administration, Department of Health and Human Services, "Link between Medicaid and SSI Coverage of Children under Welfare Reform," Fact Sheet #2, 1996b.

Health Care Financing Administration, Department of Health and Human Services, "Link between Medicaid and Temporary Assistance for Needy Families," Fact Sheet #1, 1996c.

Health Care Financing Administration, Department of Health and Human Services, "Link between Medicaid and the Immigration Provisions of the Personal Responsibility and Work Opportunity Act of 1996," Fact Sheet #3, 1996d.

Health Care Financing Administration, Department of Health and Human Services, *Section 1915(b) Freedom of Choice Waivers* (Baltimore: 1996e).

Health Care Financing Administration, Department of Health and Human Services, *Medicaid Managed Care Enrollment Report: Summary Statistics as of June 30, 1996* (Baltimore: 1997).

Holahan, John, and David Liska, *Where is Medicaid Spending Headed?* (Washington, DC: Kaiser Commission on the Future of Medicaid, December 1996).

Holahan, John, and David Liska, "The Slowdown in Medicaid Spending Growth: Will It Continue?" *Health Affairs* 16(2), March/April 1997, forthcoming.

Holahan, John, Diane Rowland, Judith Feder, and David Heslam, "Explaining the Recent Growth in Medicaid Expenditures," *Health Affairs* 12(3)177-193, Fall 1993.

Horvath, Jane, and Neva Kaye, eds., *Medicaid Managed Care: A Guide for States*, Second Edition (Portland, ME: National Academy for State Health Policy, 1995).

Horvath, Jane, and Neva Kaye, *Enrollment and Disenrollment in Medicaid Managed Care Program Management*, (Portland, ME: National Academy for State Health Policy, December 1996).

Horvath, Jane, and Neva Kaye, eds., *Medicaid Managed Care: A Guide for States*, Third Edition (Portland, ME: National Academy for State Health Policy, 1997).

Kaiser Commission on the Future of Medicaid, *Medicaid Facts: Medicaid and Managed Care*, Fact Sheet (Washington, DC: May 1996a).

Kaiser Commission on the Future of Medicaid, *Medicaid Facts: Medicaid Enrollment and Spending Growth*, Fact Sheet (Washington, DC: December 1996b).

Kaiser Commission on the Future of Medicaid, *Medicaid Facts: The Medicaid Program at a Glance*, Fact Sheet (Washington, DC: November 1996c).

Kaiser Commission on the Future of Medicaid, *Medicaid Facts: The Medicaid Program at a Glance*, Fact Sheet (Washington, DC: 1997a, forthcoming).

Kaiser Commission on the Future of Medicaid, unpublished calculations, March 1997b.

Lazenby, Helen, Katharine R. Levit, and Daniel R. Waldo, "National Health Expenditures, 1985," *Health Care Financing Notes* 6:1-32, September 1986.

Levit, Katharine R., Helen C. Lazenby, and Lekha Sivarajan, "Health Care Spending in 1994: Slowest in Decades," *Health Affairs* 15(2):130-144, Summer 1996.

Lewin-VHI, *States as Payers: Managed Care for Medicaid Populations* (Washington, DC: National Institute for Health Care Management, February 1995).

Liska, David, Karen Obermaier, Anuj Shah, and Alina Salganicoff, *Medicaid Expenditures and Beneficiaries: National and State Profiles and Trends, 1988-1994*, Second Edition (Washington, DC: Kaiser Commission on the Future of Medicaid, November 1996).

National Health Policy Forum, *Impact of the New Welfare Law on Medicaid*, Issue Brief No. 697 (Washington, DC: February 7, 1997).

Page, Leigh, "HMOs Back Away from Medicaid," *American Medical News* 40(2):3, 22, January 13, 1997.

Physician Payment Review Commission, *Annual Report to Congress 1993* (Washington, DC: 1993).

Physician Payment Review Commission, *Annual Report to Congress 1995* (Washington, DC: 1995).

Physician Payment Review Commission, *Annual Report to Congress 1996* (Washington, DC: 1996).

Sparer, Michael, and Karyen Chu, *Managed Care and Low-Income Populations: A Case Study of Managed Care in New York* (Menlo Park, CA: Henry J. Kaiser Family Foundation, October 1996).

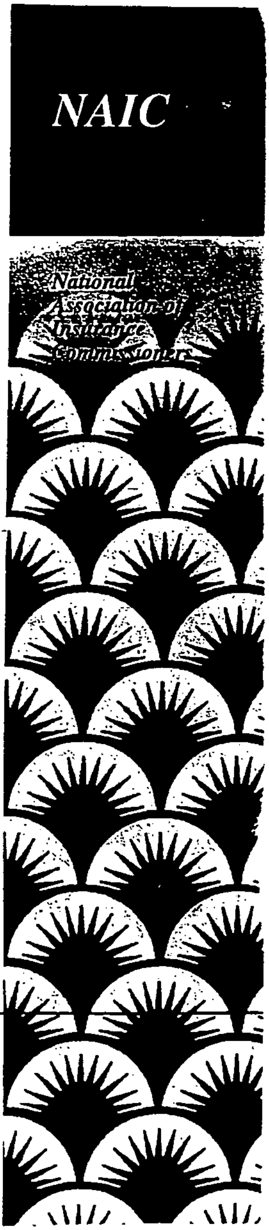
Sparer, Michael S., Marilyn R. Ellwood, and Cathy Schoen, *Managed Care and Low-Income Populations: A Case Study of Managed Care in Minnesota* (Menlo Park, CA: Henry J. Kaiser Family Foundation, May 1996a).

Sparer, Michael S., Marsha Gold, and Lois Simon, *Managed Care and Low-Income Populations: A Case Study of Managed Care in California* (Menlo Park, CA: Henry J. Kaiser Family Foundation, May 1996b).

United Hospital Fund, "The Impact of Federal Welfare Reform," *Currents: Medicaid Managed Care* 1(3), Fall 1996a.

United Hospital Fund, "New Plans Enter Program; Current Plans Also Renewed," and "Medicaid Managed Care Legislation Passed," *Currents: Medicaid Managed Care* 1(3), Fall 1996b.

Wooldridge, Judith, Leighton Ku, Teresa Coughlin, et al., *Reforming State Medicaid Programs: First-Year Implementation Experiences from Three States* (Princeton: Mathematica Policy Research, January 1997).



Medicaid Managed Care:

Perspectives of the National Association of Insurance Commissioners

Medicaid Managed Care:

Perspectives of the National Association of Insurance Commissioners

---

1996

NAIC
National Association
of Insurance Commissioners

125
Years
1871-1996
NAIC

National Association of Insurance Commissioners
Publications Department
(816) 374-7259
http://www.naic.org

Printed in the United States of America

Support & Services Office
120 W. Twelfth St., Suite 1100
Kansas City, MO 64105~~-1925~~
(816) 842-3600

Securities Valuation Office
195 Broadway
New York, NY 10007-0007
(212) 285-0010

Washington Counsel/
Government Relations/
Financial Analysis
Hall of States Bldg.
444 North Capitol NW, Suite 701
Washington, DC 20001-1512
(202) 624-7790

Background

Medicaid is a joint federal and state entitlement program which provided payment for medical services to over 32 million beneficiaries in FY 1994[3]. The program is state administered with the costs shared between the federal and state governments. The federal government provides matching funds at a percentage determined annually by the federal government generally based on each state's per capita income. Currently, the federal match for Medicaid services is set at a minimum of 50 percent and a maximum of 83 percent. Over the past few years federal funds have accounted for 57 percent of total Medicaid expenditures.[4] Medicaid spending has increased from $41 billion in 1985 to $138 billion in 1994[5].

The states have broad federal guidelines to follow in determining eligibility and coverage standards, but each state designs and administers its own Medicaid program. Medicaid beneficiaries qualify for coverage when determined to be either categorically needy or medically needy. Categorically needy persons include those receiving Aid to Families with Dependent Children and most persons on Supplemental Security Income. All of the states cover individuals in these categories. More than 75 percent of the states also provide benefits to the "medically needy"; the "medically needy" are individuals whose resources exceed the income eligibility standards for the categorically needy but who meet a separate state determined income standard. The medically needy include pregnant women, certain children, the aged, disabled, families with dependent children and those persons who "spend down" their income and assets due to large health care expenses.

Because the Medicaid program is swiftly becoming most states' largest budget item, averaging 19.4% of the average state's total expenditures in 1994,[6] states are implementing strategies designed to control Medicaid costs. According to recent surveys, states are reducing expenses for health care services by maintaining or diminishing reimbursement rates as well as curtailing covered services[7]. States are also converting their programs to managed care. More than half the states responding to a recent survey are implementing or expanding managed care programs as a way to control costs while insuring quality and access.

While most Medicaid programs are still similar to fee-for-service indemnity insurance with the state and federal government at risk for expenditures, many states have begun to seek waivers from federal Medicaid requirements in order to experiment with managed care. Under Sections 1115 and 1915(b) of the Social Security Act, the Secretary of Health and Human Services may waive certain requirements to facilitate states' use of managed care for Medicaid beneficiaries. The mechanism through which most states have enrolled Medicaid beneficiaries into managed care programs has been Section 1915(b) program waivers. Under Section 1915(b) waivers, the Secretary may waive the requirement that states

---

[3] HCFA, Office of the Actuary, FY 1994.

[4] Health Care Financing Review Medicare and Medicaid Statistical Supplement, 1995, HCFA.

[5] National Association of State Budget Officers, 1993 State Expenditure Report, March 1994.

[6] National Association of State Budget Officers, 1994 State Expenditure Report, 1994.

[7] *The State of State Medicaid Programs: Fiscal year 1994*, The American Public Welfare Association, May 1994.

INTRODUCTION

Presently, nearly one quarter of all Medicaid beneficiaries receive their health care through a managed care arrangement.[1] This movement toward managed care within the Medicaid program has occurred predominantly over the last decade.[2] With its emphasis on early intervention and preventive care, many states have looked to managed care as a means to improve access to primary care and reduce reliance on emergency rooms as a site of care. In addition, many states have hoped that managed care would help contain spiraling Medicaid costs.

State insurance regulators, together with other state officials, have significant experience in regulating managed care plans which serve the commercial population. In fact, in several states, insurance departments have exclusive regulatory authority over these plans. In others, jurisdiction is split with state health departments, or retained within a separate state agency. In either case, oversight of plan financial solvency and market practices is frequently lodged within the insurance departments. The recent and expedited shift to managed care systems for the Medicaid population has raised numerous challenges for the state and federal government. State insurance regulators note that some of these challenges parallel early experiences and problems in the developing stages of managed care systems for commercial populations. Other challenges reflect the unique characteristics of the Medicaid population.

The knowledge gained from the establishment of managed care for commercial enrollees as well as earlier efforts in developing Medicaid managed care programs has provided insight into those regulatory requirements which are relevant for managed care programs for Medicaid beneficiaries. The similarities involved in developing managed care programs for enrollees whose care is supported with private or public sector funds, warrant considering the application of state licensure requirements to commercial plans serving the Medicaid population. However, the unique characteristics of the Medicaid population, may also require that requirements specific to the needs of the Medicaid population also be applied to Medicaid managed care programs. This latter set of issues goes beyond the traditional regulatory authority of state insurance departments.

In developing Medicaid managed care programs, states must consider a broad range of issues. In this white paper, the National Association of Insurance Commissioners' (NAIC) State and Federal Health Insurance Legislative Task Force has identified several considerations primarily related to financial solvency, for policymakers involved in the design and implementation of Medicaid managed care programs. The paper also reviews changes to the Medicaid program which are currently under consideration by Congress and discusses their implications for state regulation of Medicaid managed care plans. The paper is not intended as an advocacy piece in favor of certain programs, nor does it seek to make any recommendations concerning the appropriate state regulatory body to oversee such programs. Rather, the paper seeks simply to identify and highlight areas within the expertise of NAIC members where careful and thoughtful planning and oversight are particularly warranted.

---

[1] *Medicaid and Managed Care: Lessons from the Literature*, Kaiser Commission on the Future of Medicaid at ix, 1995. (Hereinafter referred to as "KFF")

[2] Id. at 8 citing that in 1983 only three percent of the Medicaid population was enrolled in managed care.

give beneficiaries freedom of choice of providers so that states may require Medicaid beneficiaries to enroll in managed care arrangements. States have also been granted Section 1115 research and demonstration waivers. Research and demonstration waivers provide states with greater flexibility than Section 1915(b) waivers, enabling them to change a broader array of Medicaid requirements such as those related to eligibility and the scope of services available. Section 1115 waivers also impose greater administrative burdens on states so that the federal government, through an independent contractor, can evaluate the impact of the demonstration project on such matters as utilization, cost of services, as well as access and quality of the care received.[8] In addition to shifting the traditional Medicaid population into managed care, Section 1115 waivers enable states to extend Medicaid benefits to certain individuals and families not currently eligible for Medicaid coverage.[9]

As of October 1995, 14 Section 1115 waivers have been granted, to Arizona, Delaware, Florida, Hawaii, Illinois, Kentucky, Massachusetts, Minnesota, Ohio, Oregon, Rhode Island, South Carolina, Tennessee, and Vermont . In November 1995, managed care demonstration waivers were pending in 12 other states, Alabama, Georgia, Illinois, Kansas, Louisiana, Missouri, Montana, New Hampshire, New York, Texas, Utah, and the District of Columbia. As of June 1995, all but a few of the remaining states have received Section 1915(b) waivers, in all or a portion of their states.

It should be noted that states may develop a managed care program without obtaining a waiver from the federal government under certain circumstances. To do so, enrollment in the program must be voluntary and the program must operate statewide. No more than 75 percent of the enrollees in the HMO can be eligible for Medicaid or Medicare. In addition, the benefits provided to the enrollees must be comparable to the benefits the state is required to provide to all eligibility categories under federal law. While this option is available, the programs developed by most of the states require a federal waiver.[10]

In June 1994, over 7.5 million beneficiaries were enrolled in some form of managed care, more than double the number who were served in managed care arrangements just two years earlier.[11] The majority of these enrollees, almost 75 percent, were enrolled in plans with at least some capitation.[12] Due to the diversity in the evolution of managed care across the country, different states have adopted different models of Medicaid managed care.

State Medicaid managed care programs fall under three broad classifications: full-risk capitation plans, partial capitation plans, and primary care case management programs.

- Under full-risk capitation, states contract with a managed care plan for a fixed payment per person. The fee covers either inpatient hospital care plus at least one other mandatory service, or three or

---

[8] Suzanne Rotwein, Ph.D., et al., *Medicaid and State Health Care Reform: Process, Programs, and Policy Options*, 16 Health Care Financing Review 105, 116 (Spring 1995).

[9] KFF, at 9.

[10] Jane Horvath and Neva Kaye, eds., *Medicaid Managed Care: A Guide for States*, 2nd ed., (National Academy for State Health Policy, 1995), pp. 29-30.

[11] Id. at 12.

[12] Id.

more mandatory services. Full-risk contracting is characteristic of federally qualified and state-certified health maintenance organizations (HMOs), health insuring organizations (HIOs), and insurer-operated, network-style managed care organizations. Frequently, in full-risk plans that do not operate as staff model HMOs, providers and other members of practice networks are expected to bear a certain amount of the financial risk for the cost of care[13]

- In partially capitated plans, the state Medicaid program reimburses plans for a more limited set of services on a fixed payment basis and reimburses for all other services on a fee-for-service basis.

- Under the primary care case management model (PCCM), states transfer almost no risk from the Medicaid program because the providers are paid a case management fee and receive fee-for-service reimbursement for all needed medical services[14]. Under this model, primary care physicians are responsible for approving and monitoring the provision of virtually all covered services to plan enrollees.[15]

According to a recent study by Lewin-VHI, there are some important differences in the type of managed care arrangements used in Medicaid programs versus those used in the private sector[16]. This study points out that both state Medicaid programs and the private sector utilize HMOs, but that Medicaid programs also use partial capitation and PCCM models not usually found in the private sector. Furthermore, Preferred Provider Organization (PPO) plans and Point of Service (POS) plans that are common in the private sector are not utilized in Medicaid managed care primarily due to statutory limitations on a state's ability to use significant cost-sharing methods. It should be noted that numerous studies indicate low-income persons tend to not access medical services when cost-sharing is required.

The Importance of Financially Sound Medicaid Managed Care Plans

Medicaid managed care programs increase the financial risk to plans which contract with the state to serve Medicaid beneficiaries and decrease the financial risk traditionally held by the government. The increased element of risk to managed care plans requires that states place as much emphasis on the financial stability of Medicaid managed care plans, and their subcontractors, as they do in the regulation of managed care plans which provide for or arrange the provision of care for commercial patients. Traditionally, state Medicaid agencies have administered the Medicaid program without the assistance of state insurance regulators. Insurance regulators and other state officials have significant experience in licensing commercial HMOs and determining whether they meet solvency and capital requirements. The shift in the Medicaid program to managed care may prompt state Medicaid agencies, departments of insurance or other state agencies responsible for the regulation of managed care plans to capitalize on their respective expertise by collaborating in the evaluation and development of Medicaid managed care program proposals.

---

[13] Id. at 10.

[14] *States as Payers: Managed Care for Medicaid Populations*, National Institute for Health Care Management, February, 1995. (Hereinafter referred to as "Institute").

[15] KFF at 10.

[16] Institute.

In addition to shifting the financial risk in the Medicaid program from the state and federal governments to the managed care plan, states may need to consider other elements of Medicaid managed care that may impact plan financial status. Because of the range of benefits provided under the Medicaid program, managed care plans may be required to provide or arrange for the provision of services they do not typically provide. For example, while many plans are familiar with the care required for young women and children who are Medicaid beneficiaries, an increased use of managed care programs for low-income senior citizens and individuals with chronic disabilities may present new challenges. The additional services which may be required to meet the needs of these populations will necessitate that plans incur costs to expand their management and treatment capacity. Additionally, where Medicaid programs, carve-out certain services from the comprehensive benefit program, plans may be asked to manage beneficiaries' health care without control over all of the care the beneficiaries may receive. It will be important for states to evaluate the impact of carve-out strategies on costs incurred by health plans as well as upon continuity of care for beneficiaries. States should also carefully design their Medicaid managed care program to avoid incentives that will encourage plans to shift costs to non-capitated programs.

States have begun to focus more closely on the financial stability of Medicaid managed care plans and the various factors which may threaten plan financial stability. For example, Tennessee's experience with its Medicaid managed care program, TennCare, has raised a number of issues for review, many of which are directly tied to participating plans' solvency. Soon after being sworn in, Tennessee's Governor Don Sundquist, appointed a new deputy insurance commissioner to monitor the quality and financial stability of TennCare's 12 managed care organizations (MCO) and an advisory panel to make recommendations on how to improve the program[17]. One of the essential recommendations made by the advisory committee was to establish a formal mechanism for checking the financial soundness of the TennCare MCOs.

In Florida, concerns also have been raised regarding the soundness of the prepaid plans participating in its Medicaid program. Florida initially granted plans serving the Medicaid program population a three year waiver from state HMO licensure requirements. As a result of financial and quality concerns related to prepaid Medicaid plans, Florida's Agency for Health Care Administration now contractually requires plans to obtain a commercial license from the Department of Insurance by January 1, 1996. Because prepaid Medicaid plans have not been subject to state HMO licensure requirements, they have not had to conform with the same level of capital and surplus requirements applied to commercially licensed plans. Legislative efforts are currently underway to require that prepaid Medicaid plans meet the same capital and surplus requirements as commercial plans at the time they seek commercial licensure.

Through the experiences of these states and others, it has become apparent that when states experiment with Medicaid managed care it is imperative that the participating plans have managed care experience, actuarial proficiency and the critical capital reserves to ensure their longevity. The rapid enrollment of significant numbers of Medicaid beneficiaries in managed care plans has caused fierce competition and an enormous new market for managed care plans. The risk of health plan insolvency is especially present given the evolving nature of many Medicaid managed care arrangements. Such insolvencies could harm

---

[17] Health Care Reform Week, January 30, 1995.

the ability of beneficiaries to receive needed health care services, delay payment to and potentially bankrupt providers, and adversely impact state budgets already experiencing fiscal constraints.

Solvency Regulation

The Health Care Financing Administration (HCFA) requires states to monitor health plans' financial solvency. HCFA requires strict quality control mechanisms to be in place before Medicaid managed care programs can be implemented[18]. To provide guidance to states in developing financial solvency standards, HCFA recently published guidelines, *Medicaid Managed Care Solvency Guidelines for Risk-Based Managed Care Plans* in January 1995.

As suggested by the experience of states which have implemented Medicaid managed care plans as well as the outcome of various studies and the guidelines recently published by HCFA, states should be diligent in applying solvency standards and oversight procedures when designing and implementing Medicaid managed care plans. As the General Accounting Office (GAO) stated in one report,

> financial oversight of participating health plans is critical to the success of any managed care program because the financial condition and viability of a plan directly affects its ability to provide continued services. Also, a plan in financial trouble has increased incentives to underserve beneficiaries.

Together, the appropriate regulatory authorities can implement mechanisms designed to limit the risk for plans' insolvency. Mechanisms which states should strongly consider include[19]:

◆ Capital and Surplus Reserves

Insurance regulatory agencies in every state currently require that managed care plans accepting risk establish certain levels of capital reserves and solvency standards. States should set such reserve standards at a level that reflects the amount of risk being transferred to the plans. Some states, such as Arizona and Oregon, successfully carve out Medicaid managed care plans from their state licensure requirements. If a state chooses not to apply its licensure requirements to Medicaid managed care plans, it should structure its program carefully to ensure adequate monitoring of capital and surplus reserves.

◆ Careful Plan Selection

States must also be careful in deciding what type of plans may participate in their Medicaid managed care programs. Strict adherence to a prior set of criteria must be met. The criteria by which they are judged can be very broad ranging from financial standards to managerial and quality standards. Furthermore, states may want to require that all plans meet the same specifications as do commercially licensed HMOs. However, in setting such strict standards for participation, each state must take into account the existence and penetration of managed care in their state and in various regions of the state.

---

[18] General Accounting Office. *States Turn to Managed Care to Improve Access and Control Costs*, March, 1993.

[19] Much of this section is based on the work of the National Institute for Health Care Management's white paper entitled *"Health Plan Solvency Issues Under Health Care Reform"*, May, 1994.

While it is important to set meaningful standards, it is also important that the state not create prohibitive standards to participation.

◆ Risk Adjustment

Each state may also want to look at the use of risk adjusters in setting its payment rates for health plans. Risk adjusters, such as age, gender, and eligibility category (e.g. chronically disabled) are mechanisms that change the payment levels received by the plans contingent upon the risk characteristics of the beneficiaries enrolled in each plan. It should be noted that while risk adjusters may help to protect a particular plan's solvency when the plan's population has an exceptionally high percentage of high risk enrollees, they may also create a disincentive for proper utilization management if the payment rates go beyond a differential reflective of the higher risk.

◆ Actuarially Determined Payment Rates

When setting the payment rate for Medicaid managed care plans, states should set the rate at levels that reflect the cost of providing the benefits. States should also consider to what extent the payment should reflect the savings and efficiencies derived from the plans' ability to manage and control costs as determined by actuarial standards. Payment levels that are set too low can result in numerous detrimental consequences. Such consequences include plan insolvency, provider bankruptcy and lack of access for beneficiaries.

◆ Reinsurance/Stop-Loss coverage

States may also want to require that newly emerging and smaller plans which wish to participate in Medicaid managed care purchase some form of reinsurance or stop-loss coverage in order to transfer some of their risk into broader pools of risk. Through reinsurance, the plans can protect themselves either from costs above a certain threshold or from certain determined catastrophic and chronic illnesses. Such reinsurance and stop-loss protection spreads the risk for extremely high costs among other insurance arrangements. As part of this effort, it is important to set thresholds to ensure appropriate risk-sharing between health plans and reinsurers. Since some segments of the Medicaid population are likely to incur significant or catastrophic expenses because of the nature of their medical condition, reinsurance/stop-loss coverage is a particularly important form of protection. When deciding whether it is necessary to require that newly emerging and smaller plans ~~purchase~~ such coverage, states should evaluate this element in the context of the panoply of solvency protections available in that state.

◆ Transition Periods

Commentary indicates that the rapid speed in which Medicaid managed care programs have been implemented has contributed to many of the problems which Medicaid managed care programs have encountered. The complexity in the design and implementation of these programs requires that states set up reasonable transition periods to enroll the beneficiaries in to managed care plans. An appropriate transition period would give states time to build community support, educate beneficiaries about their new health-care system and allow providers the opportunity to become familiar with managed care expectations. Furthermore, a proper transition period will enable states to gain more experience in managed care, gather more reliable data with which to set correct rates, and facilitate appropriate infrastructure developments. A well-planned transition from a traditional Medicaid program to Medicaid managed care also requires the commitment of staff who have developed the appropriate expertise in the critical elements of planning and implementing managed care programs.

◆ **Hold Harmless Provisions**

Federal law requires that Medicaid beneficiaries are held harmless from financial liability if a plan becomes insolvent. States must ensure that HMOs which contract with the state to provide services to Medicaid beneficiaries are required to make adequate provision against the risk of insolvency and to assure that Medicaid enrollees are in no case held liable for debts of the HMO in the case of insolvency.

Additional Cor iderations

While the financial solvency of Medicaid managed care plans is of paramount importance to departments of insurance, Medicaid agencies, and other agencies which regulate Medicaid managed care plans, other related considerations must also be considered. The section below does not exhaust the range of issues of concern to regulators, providers and enrollees. It does provide an overview of business and contractual issues with which states must be concerned to facilitate effectively their goal of providing medical assistance beneficiaries with access to quality, cost-effective health care services.

◆ **Marketing Issues**

While marketing activities can be an important component of the process of educating the patient about health plans, it is critical that managed care marketing practices are non-coercive and are designed to provide beneficiaries with accurate information. Federal law requires that states have procedures to monitor enrollment practices of managed care plans. It also requires that prepaid health care contracts specify how the HMO will ensure that the marketing materials that it distributes are accurate and not misleading. To ensure compliance with these and other provisions, many states have developed parameters to regulate Medicaid managed care marketing practices. In August 1994, HCFA developed a set of voluntary guidelines, Medicaid Managed Care Marketing Guidelines for States, to assist states which allow health plans to engage in marketing activities.

Commercial health insurance companies may use direct and mass marketing strategies to encourage enrollment in their plans within the limitation of state statutes. In the Medicaid managed care context, door-to-door marketing has been found to be subject to abuse and has been prohibited by most states.[20] Recently, the state of New York, one of the minority of states which still permitted door-to-door marketing, has decided to ban the use of the practice by HMOs which contract to serve Medicaid patients.

Many Medicaid managed care plans use mass marketing practices and offer incentives and inducements for enrollment while mass marketing. States may wish to examine the impact of offering inducements on the integrity of the enrollment process as well as the impact of mass marketing at times other than open enrollment periods.

---

[20] GAO at 28.

The regulation of marketing practices is an important component of both state and health plans' efforts to protect consumers and to communicate the objectives of a Medicaid managed care arrangement. States should, however, be attuned to the broader impact that some marketing regulations will have on enrollment practices of plans, such as their ability to determine the populations for which they will provide or arrange health care services.

- **Issues related to auto-enrollment**

Educated consumer choice is key to the success of a managed care program. The automatic assignment of individuals either because the beneficiary did not select at all or because their first selection is closed has the potential to lead to high levels of consumer dissatisfaction and noncompliance. For Medicaid managed care programs where beneficiaries are mandated to receive care from a managed care provider, many states have measured the success of their education efforts by reviewing the assignment rate of Medicaid beneficiaries. Low assignment rates tend to indicate that beneficiaries are more content with the care provided in the program.[21] States should strive to develop and implement consumer education programs which maximize beneficiary participation.

States may also want to examine practices related to the assignment of auto-enrollment populations to low bid plans. Efforts to increase the number of enrollees assigned to a low bidder may minimize the positive benefits to the program derived from consumer choice.[22] This process also may have implications relating to the relative health risk of auto-enrolled vs. voluntarily enrolled populations, with concomitant financial implications.

- **Consequences of disenrollment trends and applicability of portability requirements**

A fundamental premise of managed care is the promotion of primary and preventive health services, plans and payors seek to achieve cost savings through this preventive investment. However, Medicaid managed care enrollments are by definition short term (half of all Medicaid enrollees lose coverage within 12 months).[23] Federal Medicaid law enables states to guarantee eligibility for a specific period of time beyond changes in a beneficiary's financial status.[24] Some states have taken advantage of this option. When considering whether to guarantee eligibility for a specific length of time, states may need to weigh the costs of guaranteeing longer eligibility against the adverse incentives that could result from shorter enrollment periods.

Several states with insurance portability requirements applicable to the commercial sector have also acted to encourage or require commercial plans to "count" Medicaid coverage when considering whether the imposition of preexisting condition limitations or waiting periods are appropriate. Ohio, for example, has a statute which recognizes all forms of health plans as satisfying the preexisting

---

[21] GAO at 27; Trish Riley et al., *Medicaid Managed Care: The State of the Art, A Guide for States* (National Academy for State Health Policy, 1990), p. 2.

[22] "Ten Key Issues for States Under Medicaid Managed Care", George Washington University Center for Health Policy Research.

[23] Id.

[24] General Accounting Office at 25.

condition period. Such requirements encourage portability for health care consumers among a broader array of plans.

◆ Health plan standards

As the health care market evolves, states regularly examine their applicable laws and regulations and suggest updates and revisions. To help facilitate state efforts in this area, the NAIC's health plan accountability working group currently is working on an effort, "CLEAR" (Consolidated Licensure for Entities Assuming Risk") which involves an examination and suggested restructuring of existing NAIC health-related and managed-care-related model laws. In addition, the working group is developing several model laws and regulations which will form a part of the "CLEAR" effort. These include models in the areas of utilization review, provider credentialing, provider contracting/access, quality assurance, data reporting, confidentiality and grievance procedures. These model laws, although tailored for the general, commercial population, may also serve as a resource for states as they develop their regulatory structures for Medicaid managed care.

◆ Consideration of the needs of special populations

The Medicaid population is a culturally diverse population consisting of persons whose lives may be disrupted by poverty, substance abuse, mental illness and chronic illness. These individuals are likely to require additional services such as outreach, language interpretation, transportation, case management, social services and child care in order to access health care provided by managed care plans.[25] When considering the contractual and operational structure of managed care arrangements, states should acknowledge the important role these activities play in ensuring access to quality health care.

◆ Public health and managed care

When designing Medicaid managed care programs, states may also want to consider including various community-based organizations as managed care providers if they meet the statutory requirements. Such entities have relationships with local communities that can assist in the development of community-based support for Medicaid managed care programs and can facilitate state efforts to reach beneficiaries effectively.[26] Additionally, the inclusion of community-based organizations in a plan's provider arrangements can assist plans in making its services accessible to plan enrollees.

◆ Nonurgent use of the emergency room

One of the principal objectives of states in designing Medicaid managed care programs is to reduce the inappropriate utilization of emergency rooms for nonurgent care by Medicaid patients. A recurrent problem with the Medicaid and uninsured populations has been the use of hospital emergency rooms for nonurgent care. Most studies have concluded that the nonurgent use of emergency room care does decline under Medicaid managed care.[27] States may need to address emergency room provider

---

[25] National Association of County Health Officials, "Managed Care, Medicaid and the Public Health System".

[26] Id.

[27] KFF at 16.

concerns which may be raised when a Medicaid beneficiary inappropriately goes to a non-participating hospital's emergency room. Hospital emergency rooms are required by federal law to determine which patients who enter their emergency room have an emergent condition and to stabilize any critically ill patient. Hospitals may seek to have the costs of such determination reimbursed and obtain assurances that the health plan will pay for the emergency care received by the Medicaid patient. Likewise, health plans may seek to ensure that they are only responsible for the cost of out-of-plan care in a true emergency. States should be aware of how payment determinations related to emergency treatment impact both hospital emergency providers and managed care plans.

Impact of Federal Medicaid Reform

The House and the Senate have recently passed a budget reconciliation bill which President Clinton has vowed to veto. This legislation includes substantial changes to the Medicaid program. The Congressional provisions repeal Medicaid and create a new MediGrant program. Through this approach, Congress seeks to eliminate the federal entitlement status to Medicaid and convert federal payments to states into a block grant.

Under the Congressional block grant plan, states would be provided with considerable flexibility to define eligibility and benefits. The bill specifically grants states the power to decide which items or services will be covered under the MediGrant program. It does require that states include coverage for immunizations for children. States are mandated to provide medical assistance to pregnant women and children under age 13 who live in families under 100 percent of the poverty level, and to any individual who is disabled. The state would be responsible for defining the term disability. All other categories of eligible individuals will receive services at the discretion of the state. However, the bill does require the states to set-aside a certain percentage of funds to be devoted to services provided to low-income families, low-income elderly and low-income disabled, as well as federally qualified health centers and rural health clinics.

The Congressional plan also enables states to design innovative program delivery structures, including managed care arrangements, without having to undergo a waiver process.

The bill does impose some requirements upon states which contract with capitated health care organizations[28]. If a state contracts with capitated health care organizations to provide medical care to Medicaid recipients, and the organization is under full financial risk, the state must require that the organization meet the solvency standards established by the state for private organizations. If the capitated health care organization is not at full financial risk, the state must require that it meets solvency standards established under the state's MediGrant plan. This requirement is not applicable to public entities or those entities whose solvency is guaranteed by the state.

---

[28] A capitated health-care organization is defined as "a health maintenance organization or any other entity (including a health maintenance organization, managed care organization, prepaid health plan, integrated service network, or similar entity) which under state law is permitted to accept capitation payments for providing (or arranging for the provision of) a group of items and services including at least inpatient hospital services and physicians' services. Sec. 2114 (c)(1).

If a state contracts with or intends to contract with a capitated health care organization and makes a capitation payment[29] to the organization for providing MediGrant services, including at least inpatient hospital services and physician services, the state's MediGrant plan must include a description of the use of actuarial science in projecting expenditures, utilization for enrollees, and setting capitation payment rates. States are also required to describe the qualifications that participating plans must meet, including whether it must obtain a state license, or be accredited or certified in order to participate as a capitated health organization in the MediGrant plan. In addition, states must develop a process for disseminating to contractors the information on capitation rates and historical fee-for-service cost and utilization data.

Unlike the traditional Medicaid program, the MediGrant bill does not specifically prohibit significant cost-sharing[30] requirements. It does require that states provide a public cost-sharing schedule listing of any charges which may be imposed. Limitations are placed on cost-sharing arrangements which may be applied to services for children and pregnant women.

The benefits derived from increased flexibility and less onerous administrative burdens is accompanied by the challenges most states will face as they take on this additional responsibility with a gradually lowering in the level of funding that they will receive from the federal government over the coming years. Block grants may further encourage state implementation of managed care programs for medical assistance beneficiaries to facilitate cost control efforts.

The ultimate outcome of the national debate on how the federal government will finance medical assistance will be determined over the coming weeks through negotiations between Congress and the Clinton Administration. Whether a state is operating under the traditional Medicaid program, a block grant program, or an alternative structure, the basic building blocks to a strong managed care program for medical assistance beneficiaries, previously mentioned in this document, remain the same. The development of any successful managed care plan which facilitates access for a range of medical assistance beneficiaries to quality health care services requires strong financial oversight by the state agencies responsible for managed care programs, sound actuarially determined payment rates which reflect the costs of providing care and the savings derived from managed care initiatives, and sufficient monitoring of plan marketing and other strategies to enroll participants. Particularly important in a new system will be an adequate time period for transitioning. Proper time to phase-in to a managed care plan will enable state agencies to develop the infrastructure necessary to accommodate changes and give providers, enrollees and other members of the community time to provide input into the process and to adjust to a new managed care system. Appropriate staff expertise familiar with operational, financial and contractual structures of managed care arrangements will be critical to this endeavor.

---

[29] A capitation payment is defined as "payment on a prepaid capitation basis or any other risk basis to an entity for the entity's provision (or arranging for the provision) of a group of items and services, including at least inpatient hospital services and physicians' services. Sec. 2114(c)(2).

[30] Cost-sharing is defined to include "copayments, deductibles, coinsurance, and other charges for the provision of health care services. Sec. 2113(d).

Conclusion

Over the past decade, managed care arrangements have become a viable alternative to states seeking innovative strategies to provide medical assistance beneficiaries with quality health care in a cost-effective manner. Designing and implementing a Medicaid managed care program involves a plethora of issues which the states, providers and citizens must address. Many of the basic components for the development of a sound Medicaid managed care program remains the same irrespective of whether the public Medicaid assistance plan is a federal-state matching program or a block grant. Among the range of significant concerns, ensuring the financial solvency of Medicaid managed care plans is prominent. Ensuring financial solvency involves not only setting meaningful capital and reserve requirements but establishing standards and monitoring adequately the business practices of plans. Regulators in state insurance departments, Medicaid agencies, or other applicable agencies may have areas of expertise the contribution of which will facilitate state efforts to design an effective program. By working with providers and citizens within the state, states regulators will maximize their ability to balance the goals of protecting consumers, disseminating information to all concerned parties about the new managed care system, and facilitating the ability of managed care plans to perform their contractual obligations effectively.

Appendix A

State Activity*

Many states have acquired significant experience in the design and implementation of Medicaid managed care programs. As states evaluate or develop their own programs, it may be useful to consider how other states have addressed certain issues. State experience in the areas of risk adjustment, reinsurance, and transition periods have been highlighted below.

Risk Adjustment:

According to a study prepared by the Project HOPE Center for Health Affairs, *Medicaid Managed Care Program Access Requirement: Final Report to the Prospective Payment Assessment Commission*, several states, including Arizona, Florida, Massachusetts and Oregon, provide separate capitation rates for enrollees in different Medicaid eligibility categories.

Reinsurance:

Some Medicaid managed care programs developed by states with Section 1115 waivers, including Arizona, Delaware, Massachusetts, and Minnesota, have reinsurance provisions.

Transition Periods:

Some states have implemented their Medicaid managed care programs on a phased-in basis. For example, Oregon enrolled AFDC recipients in 1994 and phased in enrollment of elderly and disabled populations, individuals needing mental health and chemical dependency services, and foster children during 1995.

Vermont's Medicaid managed care program is designed to include a three-year phase-in period. As planned, the program will enroll AFDC recipients and persons with incomes at or below the poverty line in 1996. Beginning in 1997, Supplemental Security Income (SSI) recipients and persons with incomes between 100 percent and 125 percent of poverty are to be enrolled. In 1998, state residents with incomes between 126 percent and 150 percent of poverty may enroll.

Unlike Oregon and Vermont, Connecticut enrollees are being phased-in on the basis of geographic area instead of by eligibility category.

*Source: Group Health Association of America

United States General Accounting Office

GAO

Report to the Chairman and Ranking Minority Member, Subcommittee on Medicaid and Health Care for Low-Income Families, Committee on Finance, U.S. Senate

July 1996

MEDICAID MANAGED CARE

Serving the Disabled Challenges State Programs

GAO
United States
General Accounting Office
Washington, D.C. 20548

Health, Education, and
Human Services Division

B-271532

July 31, 1996

The Honorable John H. Chafee
Chairman
The Honorable Bob Graham
Ranking Minority Member
Subcommittee on Medicaid and Health Care
for Low-Income Families
Committee on Finance
United States Senate

This report, prepared at your request, describes state efforts to include disabled Medicaid beneficiaries in prepaid managed care programs.

We are sending copies to the Secretary of Health and Human Services; the Administrator, Health Care Financing Administration; and state Medicaid directors. We will also make copies of this report available to others on request.

Please contact me at (202) 512-7114 if you or your staff have any questions. Major contributors to the report are listed in appendix I.

William J Scanlon

William J. Scanlon
Director, Health Financing and Systems Issues

Executive Summary

Purpose

Prepaid managed care plans, which deliver medical services for a fixed (or "capitated") per-person fee, are an increasingly common part of Medicaid, the nation's largest health care program for the poor. With their emphasis on primary care, restricted access to specialists, and control of services, prepaid plans are seen as a way to help control spiraling Medicaid costs, which totaled $159 billion in fiscal year 1995. Thus far, states have extended prepaid care largely to low-income families—about 30 million individuals—but to few of the additional 6 million Medicaid beneficiaries who are mentally or physically disabled. Managed care's emphasis on primary care and control of service use differs from the care needs of disabled beneficiaries—many of whom need extensive services and access to highly specialized providers, which in some cases are essential to prevent death or further disability. However, because over one-third of all Medicaid payments go for their care, greater attention is being focused on whether disabled individuals can be integrated successfully into managed care.

These efforts affect three key stakeholder groups: disabled beneficiaries, who include a small number of very vulnerable individuals who may be less able than others to effectively advocate on their own behalf for access to needed services; the prepaid care plans, which are concerned about the amount of financial risk involved in treating people with extensive medical needs; and the states and federal government, which run Medicaid. The Chairman and Ranking Minority Member of the Subcommittee on Medicaid and Health Care for Low-Income Families, Senate Committee on Finance, asked GAO to examine (1) the extent to which states are implementing Medicaid prepaid managed care programs for disabled beneficiaries and (2) the steps that have been taken to safeguard the interests of all three stakeholder groups. GAO's review of safeguards focused on two areas—efforts to ensure quality of care and strategies for setting rates and sharing financial risk.

Background

Medicaid is funded jointly by the states and the federal government and operated mainly by the states. It provided health care coverage for 40 million people in fiscal year 1995, about one in seven of whom was disabled. Some categories of mildly disabled individuals have health care costs that closely mirror those of the general population, but others, such as those with cystic fibrosis or end-stage acquired immunodeficiency syndrome (AIDS), have costs that are much higher.

Medicaid has traditionally been a fee-for-service program, meaning that doctors, hospitals, and other providers are paid based on the number and type of services they provide. States have relatively wide latitude in structuring Medicaid programs, including making prepaid care available to those who wish to enroll. But states must obtain federal approval to require prepaid plan enrollment or to restrict individuals to specific plans. This approval is designed to help ensure that everyone who is eligible has access to care.

Results in Brief

Serving disabled beneficiaries through Medicaid managed care poses complex, new challenges to the states. To date, few states have significant experience with prepaid care for disabled Medicaid beneficiaries, many of whom have chronic conditions that require ongoing and costly specialty care. Of the six states that require some or all of their disabled population to enroll in prepaid care, only one program is more than 3 years old. Eleven others have voluntary programs enrolling a small percentage of disabled beneficiaries. However, because of continued concern about cost containment, 13 more states have submitted proposals to enroll disabled beneficiaries in prepaid care, with 12 of them intending to make enrollment mandatory.

One of the challenges for states is developing both the service networks and the necessary assurances that the health care needs of disabled beneficiaries are being met appropriately. However, about half of the states tend to rely on mechanisms such as the freedom of disabled individuals to disenroll from or switch prepaid plans or on their access to the states' and plans' complaint and grievance systems to help ensure quality of care. While analyses of patterns of disenrollment or complaints can provide meaningful information, in the aggregate they may not be sufficient to detect systemic deficiencies in care for disabled beneficiaries. In contrast, states that either mandate enrollment or provide small, voluntary programs focused exclusively on disabled beneficiaries tend to be furthest along in developing assurances that appropriate, quality care is available to them. Examples of such actions include requiring health plans to designate advocates to help coordinate the services disabled beneficiaries receive and to provide access to specialists specifically trained in care for disabled individuals.

A second challenge for states is developing and administering a managed care system for disabled beneficiaries that is financially sound. However, few states have ventured beyond current rate-setting approaches that base capitation rates on average costs for large segments of statewide Medicaid populations, such as families with children or disabled individuals. However, within the disabled population some groups, such as quadriplegics or AIDS patients, have substantially higher medical costs (sometimes more than $50,000 in a given year), while others, such as mildly disabled individuals, may have few or no additional costs beyond those of the general population. The ability to identify individuals with high-cost disabilities could lead managed care plans to try to avoid enrolling them or to encourage them to disenroll by limiting services inappropriately. The development of more appropriate rate-setting approaches that link rates more closely to individuals' likely costs is still in the experimental stage. States are further along in adopting methods to share the risk of losses experienced by plans that enroll a relatively large number of high-cost individuals. For example, reinsurance programs are the most common form of sharing such losses. A few states are adopting an approach called a "risk corridor," which limits the amount of profit that health care plans can earn as well as the amount of loss they could face, thereby reducing the incentive to inappropriately limit services or to avoid enrolling high-cost individuals.

Principal Findings

Few States Have Significant Experience

Arizona, Delaware, Oregon, Tennessee, Utah, and Virginia are the only states requiring some or all of their disabled beneficiaries to participate in prepaid care programs. These states enroll disabled beneficiaries in prepaid managed care plans that also cover other types of Medicaid recipients. Arizona's program, established in 1982 and currently enrolling more than 70,000 disabled, is the only mandatory program more than 3 years old. In contrast, Massachusetts, Ohio, Wisconsin, and the District of Columbia have small-scale voluntary programs solely for disabled individuals, none of which serves more than 3,000 beneficiaries. Seven other states (California, Colorado, Florida, Maryland, Michigan, New Jersey, and Pennsylvania), as well as Massachusetts, allow disabled beneficiaries to enroll voluntarily in plans open to other Medicaid beneficiaries. In these states, less than 20 percent of the disabled population have chosen to enroll.

One problem identified thus far in states with federal approval to restrict beneficiaries' freedom to change providers has been coordinating enrollment for the estimated one-third of disabled individuals who are "dually eligible" for health care under Medicaid and Medicare. Medicare law guarantees these individuals more freedom in switching providers than they have under Medicaid managed care programs, which require prepaid plan enrollment. The few states wrestling directly with this issue have taken varying approaches, ranging from adjusting their programs to conform with Medicare requirements to seeking waivers of Medicare law that would allow requirements closer to Medicaid's.

Significant Efforts Needed to Ensure Quality

States that rely on monitoring the services prepaid care plans provide to the average enrollee may find that these efforts do not provide enough specificity for assessing care received by disabled enrollees. For example, problems in care provided to a very vulnerable disabled category, such as quadriplegics, might escape general view because few if any cases of quadriplegia would generally appear in random samples across the entire population served by a health care plan. Most states recognize a need to specifically monitor managed care for disabled enrollees and plan to do so as they expand their programs.

Important aspects of states' quality assurance activities can fall into two main categories: (1) building safeguards into the programs through adequate planning and consensus-building and (2) tailoring various aspects of the program (such as enrollment and monitoring) to meet the specific needs of disabled beneficiaries. To date, most of the efforts have been made by several states with mandatory participation by disabled individuals or by states with programs targeted exclusively to disabled beneficiaries on a voluntary basis. The following are examples:

- Oregon's Medicaid staff met weekly with health plans, advocates for disabled individuals, and others for more than a year before the program was implemented.
- Wisconsin requires the health plan serving participants in its targeted prepaid care program, which serves only disabled beneficiaries, to have a Medicaid advocate on staff who is knowledgeable about disabilities. Wisconsin also mandates that case managers conduct needs assessments within 55 days of enrollment in the plan.
- Massachusetts allows specialists to act as primary care providers and uses a health needs assessment that assists enrollment staff in working with beneficiaries to select a plan.

Information about the services provided to disabled patients is essential for effective monitoring. Since services are no longer paid for on a fee-for-service basis, however, the reimbursement process no longer produces this information. Developing comprehensive, consistent data on services provided under prepaid care takes time and effort. To date, only Arizona has substantial experience in doing so. The effort, which can be expensive and time-consuming, can permit states to identify areas in which service utilization rates are overly low or high. It can also allow states to track movement of high-cost individuals among health plans, a step that could help spot service delivery problems.

Experimentation Is Under Way in Rate-Setting and Risk-Sharing

Prepaid care capitation rates are normally based on average costs for broad categories of beneficiaries, such as all disabled people in a state. However, some categories of disabled individuals have very high costs, while others have relatively low costs. Paying the same rate for groups with different health care needs increases the risk that plans will seek to enroll only the healthier, less expensive individuals. If plans feel financial pressure from treating high-cost cases, they may also seek to limit inappropriately the services these individuals receive. Three states (Massachusetts, Missouri, and Ohio) are experimenting with ways to set rates for disabled enrollees that more accurately reflect their varying needs for care. For example, Ohio is exploring an approach that varies the prepaid rate based on prior medical costs, with medical plans receiving more money for people with demonstrated higher needs.

Most states that include disabled beneficiaries in prepaid care, and especially those with mandated enrollment, provide some form of "safety net" for plans that experience losses related to treating high-cost cases. The most common form is called "reinsurance"—essentially an insurance policy that plans can buy. Reinsurance is directed only at losses. Five states (District of Columbia, Massachusetts, Ohio, Utah, and Wisconsin) have implemented another type of arrangement, called a "risk corridor," that not only shares losses between the plan and the state but also restricts how much of its capitation payments the plan can retain after paying for enrollees' health care needs. In Massachusetts, for example, plans serving those who are severely disabled must return to the state any profit that exceeds 10 percent of the capitation payments they received. Under a risk corridor, a plan's incentive to limit services inappropriately and thereby increase the amount it may retain is reduced because such amounts are limited to a maximum.

Recommendations

GAO is not making recommendations in this report.

Agency Comments

GAO provided a draft of this report to the Administrator, Health Care Financing Administration (HCFA), and to Medicaid officials from the 17 states in its study. In addition, GAO requested comments from several independent experts in the fields of Medicaid and prepaid care for people with disabilities. HCFA had no comments, while comments from states and researchers were primarily technical or clarifying and were incorporated as appropriate. Officials from one state commented that the draft seemed to question the suitability of prepaid managed care for people with disabilities. GAO believes, rather, that careful attention to program design and implementation is needed when including this vulnerable population in prepaid care, given their complex health care needs and the limited experience to date with serving them in prepaid settings.

Contents

Chapter 4 Risk-Adjusted Rates and Risk-Sharing Can Help Reduce Incentives to Underserve Disabled Beneficiaries

Chapter 5 Observations, Conclusions, and Comments

Appendix

Tables

Figures

Abbreviations

AFDC	Aid to Families With Dependent Children
AIDS	acquired immunodeficiency syndrome
CMA	Community Medical Alliance
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HIV	human immunodeficiency virus
HMO	health maintenance organization
ICF/MR	intermediate care facility for the mentally retarded
IMD	institution for mental diseases
NF	nursing facility
SSI	Supplemental Security Income

Chapter 1

Background

Medicaid, a joint federal-state health financing program for the poor, provided health care coverage for more than 40 million people in fiscal year 1995. Medicaid expenditures—about $159 billion in fiscal year 1995[1]—have more than tripled in the past 10 years. Under current projections, they will double again within 8 years.

To help constrain rising costs, a number of states are making increased use of prepaid managed care in their Medicaid programs. Under this approach, a medical plan such as a health maintenance organization (HMO) agrees to make a specified set of medical benefits available in exchange for a prepaid amount of money per person. This approach is considered less expensive than the traditional fee-for-service approach because it eliminates the incentive to provide unnecessary or overly expensive services in order to maximize revenues.

Thus far, most states have focused their Medicaid managed care efforts on programs for low-income families, which accounted for about 73 percent of Medicaid beneficiaries in fiscal year 1994. However, states are now directing more attention to using managed care for another group of Medicaid beneficiaries—those who are disabled. These individuals constitute about 15 percent of all Medicaid beneficiaries, but because many of them have a heavy need for specialized medical services, they account for over one-third of all Medicaid expenditures.

For a number of reasons, such as their ongoing dependence on specialized care and the wide diversity of types and severity of conditions, bringing disabled people into managed care presents challenges that differ from covering many other segments of the population. Dealing with these challenges involves ensuring that adequate mechanisms are in place to safeguard the interests of all three major stakeholder groups: the disabled beneficiaries, who are concerned about adequate access to quality care; the managed care plans, which are concerned about not assuming inappropriate or excessive financial risk; and the states and federal government, which are concerned about protecting the interests of both beneficiaries and taxpayers. For the most part, this is new territory: Most states have little or no experience in adjusting their managed care programs to meet these specialized needs.

---

[1] Amounts include both health services and administration for federal fiscal year 1995, which ended Sept. 30, 1995.

Disabled People Are One of Several Groups Eligible for Medicaid

The range of services provided under Medicaid varies from state to state. Established in 1965 as title XIX of the Social Security Act (42 U.S.C. 1396-1396s), Medicaid programs are required under federal law to provide eligible beneficiaries with certain primary, acute, and long-term care benefits. Examples include physician services, hospital care, laboratory services, preventive care for children, and nursing facility care. At their option, states[2] may also elect to provide coverage for an array of other services, such as prescription drugs, medical equipment, eyeglasses, dental care, and ancillary services such as physical and speech therapy. Medicaid is administered at the state level, with the Health Care Financing Administration (HCFA) within the Department of Health and Human Services (HHS) providing oversight and coordination at the federal level.

Those eligible for Medicaid come primarily from two cash assistance programs: Aid to Families With Dependent Children (AFDC) and Supplemental Security Income (SSI). AFDC is the primary route by which children and their families become eligible, while elderly, blind, and disabled individuals become eligible primarily through SSI. Coverage expansions since 1984 have also increased the number of beneficiaries not linked to cash assistance payments. These include people who are eligible for Medicare, low-income children and pregnant women who are not receiving AFDC, and several mandatory and optional coverage groups among disabled and elderly individuals.

About 6 million disabled individuals were covered by Medicaid in fiscal year 1994. To qualify for SSI—and therefore for Medicaid in most states[3]—beneficiaries must meet certain program criteria for disability and for maximum allowable financial resources. Eligibility criteria center on an individual's ability to function in daily life and the existence of a disabling diagnosis or condition.[4] In 1996, the maximum allowable income was $470 per month for an individual and $705 for a couple.[5] States have

---

[2] Besides the 50 states, 6 other entities have programs: the District of Columbia, American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, and the Virgin Islands. For this report, we refer to all 56 as "states."

[3] Eleven states elect to retain the more restrictive Medicaid eligibility criteria that were in place for blind, disabled, and elderly beneficiaries before SSI was established in 1972. These states may use more restrictive definitions of disability or more restrictive financial eligibility criteria than SSI.

[4] Specifically, a disabled person is one who is unable to engage in any substantial gainful activity because of a medically determined physical or mental impairment that is expected to result in death or that has lasted (or can be expected to last) at least 12 months. Eligibility for children is based on developmental delays and functional impairment.

[5] Maximum financial assets exclusive of a home, automobile, burial space(s), and personal effects were $2,000 for an individual and $3,000 for a couple.

the option of extending eligibility to people who receive state payments that supplement SSI benefits;[6] to some people whose incomes are above SSI levels but who are sufficiently disabled to need institutional care; and, with federal approval, to some people who are at risk of needing institutional care. For 1996, the federally specified maximum income level for an "SSI-related" individual was $1,410 per month.

More than half of all disabled people receiving SSI as of December 1994 were eligible on the basis of a mental disability. Such disabilities included mental retardation, autism, schizophrenia, paranoia, and, under certain circumstances, substance abuse.[7] For those who were eligible on the basis of physical disabilities, the main categories were diseases of the nervous system, sense organs,[8] musculoskeletal and connective tissues, or circulatory system. Specific conditions in these categories included blindness, muscular dystrophy, cerebral palsy, Parkinson's syndrome, brain tumors, rheumatoid arthritis, osteoporosis, and chronic heart disease.

Children constitute about 22 percent of disabled SSI recipients. Among them, mental retardation is the leading cause for eligibility. Since a 1990 U.S. Supreme Court decision,[9] SSI disability criteria for those 18 and younger have been based on developmental delays and limitations in ability to engage in age-appropriate activities.

Disabled People Account for Over One-Third of Medicaid Expenditures

Many disabled Medicaid beneficiaries have a level of medical need that is atypical of the general population. A disabled person's degree of disability can range from mild to very severe. At the more severe levels, individuals may be technology-dependent, requiring medical devices to compensate for loss of a vital body function. Many of them also require ongoing nursing care to avert death or further disability.

Because of their atypical medical needs, disabled individuals have medical costs that are generally higher than those of the typical Medicaid beneficiary. In fiscal year 1994, disabled individuals were about 15 percent

---

[6] In some cases, states are required to provide supplemental payments. In February 1994, less than 0.1 percent of SSI recipients qualified for these required payments.

[7] Drug or alcohol addiction by itself does not qualify an individual for SSI benefits. Rather, individuals must be disabled (as defined by SSI law) with addiction as a factor contributing to the disability.

[8] Because blindness is included among disabilities of the sense organs, throughout this report we will refer to blind and disabled beneficiaries collectively as disabled.

[9] Sullivan v. Zebley, 493 U.S. 521 (1990).

of the Medicaid population and accounted for 39 percent of Medicaid expenditures, including long-term care. Table 1.1 shows an Urban Institute analysis of how expenditures for different services in 1993 were distributed on a per-person basis. Average total expenditures for disabled ($7,956) and elderly individuals ($9,293) were each more than three times the spending for other children and adults.

Table 1.1: Average Medicaid Per-Person Expenditures by Beneficiary Group, 1993

	Primary and acute care						
Beneficiary group	**Inpatient**	**Physician, lab, X ray**	**Outpatient**	**Other[a]**	**Total**	**Long-term care[b]**	**All services**
Disabled	$2,072	$443	$773	$1,183	$4,471	$3,485	$7,956
Elderly	541	139	155	793	2,385[c,d]	6,907	9,293[c]
Other adults	805	381	304	313	2,041[c,d]	27	2,067[c]
Other children	452	159	165	203	1,116[c,d]	74	1,191[c]

Note: Some data on this table are estimates made by the Urban Institute to correct problems in data reported to HCFA by states.

[a] Includes prescription drugs, case management, family planning, dental, children's preventive services, vision, and other practitioner care (such as therapy).

[b] Long-term care includes institutional care, inpatient mental health care, and home health services.

[c] Totals do not add because of rounding.

[d] Totals do not sum from the listed services because they include payments to Medicare and prepaid health plans that cannot be assigned to specific services.

Source: Urban Institute calculations based on HCFA data.

Managed Care Is Growing Throughout the Medicaid Program

In general terms, managed care refers to a range of health care models that use primary care practitioners to control and coordinate the delivery of services. The best-known options are prepaid (or "capitated") models that involve payment of a set monthly amount per enrollee (the capitation fee) to provide or arrange for a specified set of services.[10] Faced with rising Medicaid expenditures—the fastest-growing portion of most state budgets—many states have begun to incorporate managed care into their service delivery approach. Managed care is seen as a way to help control these costs because it discourages providers from providing unnecessary

---

[10] Other managed-care options include primary care case management models, which are similar to traditional fee-for-service arrangements except that providers generally receive a per capita case management fee to coordinate the care for enrolled patients in addition to reimbursement for each service they deliver.

services and directs beneficiaries to obtain care in the most cost-effective settings (for example, obtaining primary care at a clinic rather than a hospital emergency room).

Managed care is also seen as a way to better ensure that Medicaid beneficiaries have access to quality care. In theory, managed care improves access and quality by linking individual beneficiaries with a single provider responsible for coordinating their health care needs. Our earlier review of these efforts found that the capitated managed care programs were succeeding, at least to some degree, in providing the kinds of benefits for which they had been designed. We found access to care was slightly better than in traditional fee-for-services programs and quality was about equal between the two.[11]

In June 1995, almost 15 percent of all those who received Medicaid services were enrolled in prepaid managed care plans.[12] Their numbers, while still small in relationship to the total number of beneficiaries, are growing swiftly. For example, from June 1993 to June 1995 enrollment in capitated plans more than doubled, from 2.1 million to 5.3 million.

To date, most states have largely targeted their managed care programs—particularly those that require enrollment in prepaid plans—to children and adults who qualify for Medicaid through AFDC or other programs, not toward elderly and disabled individuals. However, states are increasingly including—or planning to include—disabled and aged populations as well.

Federal Requirements Govern State Use of Managed Care in Medicaid

A key feature of state Medicaid programs historically has been beneficiaries' freedom to choose from among participating providers. While this freedom helped protect quality because beneficiaries who felt the care they received was inadequate or inferior could simply change providers, it did not guarantee that providers would be available to treat them. Managed care approaches attempt to guarantee access to a provider but often in exchange for some limitation on beneficiaries' freedom of choice. The extent to which state Medicaid managed care programs restrict beneficiaries' choice of providers determines, in part, whether

---

[11] Medicaid: States Turn to Managed Care to Improve Access and Control Costs (GAO/HRD-93-46, Mar. 17, 1993).

[12] The percentage enrolled would be somewhat lower if calculated on the number of people eligible to receive services rather than those who actually did. Data on the number of eligible people in fiscal year 1995 were not available.

states will need to seek approval from HCFA to waive one or more provisions of Medicaid law.

States have three options for using capitated managed care plans in their Medicaid programs—one that requires no waiver of Medicaid statute and two that do. Since the late 1960s, states have had the option—with no need for a waiver—to contract with prepaid managed care plans to deliver health care services to Medicaid beneficiaries, provided certain conditions are met. One is voluntary enrollment: Beneficiaries must ordinarily be permitted to disenroll at any time and return to the Medicaid fee-for-service program.[13] Other conditions relate to such matters as the kinds of plans that can participate: They must be federally qualified or state-certified HMOS,[14] have a mix of enrollment that is no more than 75 percent Medicaid/Medicare enrollees, and engage in a range of quality assurance activities.

The other options for using managed care exist under waiver authorities granted to the Secretary of HHS. These authorities allow the Secretary to waive certain statutory requirements—including the beneficiaries' freedom to choose from among participating providers—so that a state can develop alternative methods of service delivery or reimbursement. These waivers are of two general types—program[15] and demonstration.[16] Table 1.2 compares various characteristics of the two types of waivers. Although managed care approaches and mandated enrollment (that is, a program that requires Medicaid participants to select among managed care approaches) can be authorized under either type of waiver, waiving the federal regulations concerning the types and enrollment mix of prepaid organizations can only be done under a demonstration waiver.

---

[13] An exception exists for federally qualified HMOs and certain other federally designated organizations. After a 1-month trial period has passed, states may restrict an enrollee's ability to disenroll for 5 months.

[14] A limited set of other organizations also qualify, such as certain types of federally designated community health centers.

[15] Program waivers are of several types, all of which are authorized under section 1915 of the Social Security Act.

[16] Demonstration waivers are also known as section 1115 waivers, after the portion of the Social Security Act that authorizes them.

Table 1.2: Comparison of Managed Care Flexibility Under Program and Demonstration Waivers

Program waivers	Demonstration waivers
General characteristics	
Allows for waiver of a limited set of Medicaid requirements	Allows for waiver of nearly any provision in Medicaid law
Approval is generally based on meeting certain established conditions	Approval is based on the discretion of the Secretary of HHS
Waivers can be renewed for 2- to 5-year periods	Generally not renewable[a]
Generally used to establish primary care case management programs and home and community-based service programs	More recently used to establish broad changes in Medicaid programs
Characteristics pertaining to prepaid managed care	
Prepaid plans must still meet federal requirement for 25% or more private enrollment	Prepaid plans may enroll Medicaid patients exclusively
Full range of mandatory services must be offered	Benefit package may be modified[b]
Prepaid plan enrollment "lock-in" limited to 1 month[c]	Prepaid plan enrollment "lock-in" may be extended to 12 months
No restrictions on access to family planning providers	Access to family planning providers may be restricted

[a] The Congress has authorized renewal of some demonstration waivers.

[b] To date, only Oregon has been permitted to modify the benefits package for traditional Medicaid beneficiaries. Other states have been permitted to offer a modified package only to those newly eligible for Medicaid coverage under the demonstration.

[c] Lock-in is 6 months for prepaid plans meeting certain federal requirements.

The use of prepaid managed care to provide health care for disabled beneficiaries is also affected by the statutory requirements of other programs besides Medicaid. Specifically, because many disabled Medicaid beneficiaries are simultaneously eligible for one or more other federal programs—most notably Medicare[17]—state prepaid programs must accommodate requirements of these other programs. The Medicare statute, in particular, contains a number of provisions that cannot be waived and that directly affect basic features of Medicaid prepaid care. For example, the Medicare statute requires participating health plans to have an enrollment mix with no more than 50 percent publicly insured

---

[17] Medicare, authorized by title XVIII of the Social Security Act, is a federal health insurance program that covers most people aged 65 or older, all people who receive Social Security disability benefits for 24 months or more, and most people who suffer from kidney failure. Medicare consists of two parts: part A, which covers inpatient hospital, skilled nursing care, home health, and hospice services, and part B, which covers physician and a wide range of other services, including physical therapy.

enrollees, in contrast to Medicaid's allowance for up to 75 percent publicly insured members.

Applying Managed Care to Disabled Beneficiaries Poses Additional Challenges

Interest in using prepaid managed care programs for disabled Medicaid beneficiaries has prompted concerns about whether this approach is suitable to meet the needs of disabled beneficiaries. One positive viewpoint is that disabled individuals have much to gain from managed care because of its guarantee of access to a primary care practitioner and its potential for coordinating an array of available services. Improved access may particularly benefit segments of the disabled population that have historically been unable to locate practitioners willing to serve them. However, because prepaid plans typically emphasize primary care, limit access to specialty care, and carefully control the utilization of services as ways to control costs and manage care, they are potentially disadvantageous to certain disabled beneficiaries because of their need for extensive services and access to a range of highly specialized providers. For example, compared with nondisabled children in the general population, disabled children use twice as many physician visits and prescribed medications and five times as many other services, such as physical therapy. Among Medicaid children, the average per-person health care costs in 1992 were seven times higher for disabled than for nondisabled children. Other estimates place the per-person cost for moderately disabled individuals at two to three times the cost for nondisabled individuals.

The "medical necessity" standards within many prepaid plans are one example of the potential problems that disabled individuals may face, according to advocacy groups. While not unique to prepaid care, these standards often call for "substantial improvement" or "restoration of function" as conditions for recommending therapies or certain types of medical equipment. However, many disabled people have conditions that preclude making substantial improvement or restoring functions. Advocacy groups worry that medical necessity standards may restrict disabled people from receiving therapy or equipment when they need it basically to maintain their existing level of functioning or to substitute for lost functioning. Advocacy groups have also raised concerns about the potential for managed care plans to disrupt the network of providers that disabled persons have assembled over time.

Another concern that has been raised about using managed care for disabled people is the potential effect on what could be called the "perverse incentives" inherent in a prepaid managed care approach.[18] While incentives in a fee-for-service system may encourage a provider to deliver too many services, prepaid programs may encourage health plans to deliver fewer, or less expensive, services than enrollees need, such as using a physical therapist skilled in sports medicine rather than in specific disabilities such as spinal abnormalities.

Objectives, Scope, and Methodology

The Chairman and Ranking Minority Member of the Subcommittee on Medicaid and Health Care for Low-Income Families of the Senate Committee on Finance asked us to examine (1) the extent to which states are implementing prepaid Medicaid managed care for disabled beneficiaries and (2) what steps states have taken to safeguard the interests of the three major stakeholder groups—disabled beneficiaries, prepaid health care plans, and the government—with a focus on quality assurance and rate-setting mechanisms. On the basis of discussions with subcommittee staff, we focused our review on the delivery of primary and acute medical services. We also focused our work on prepaid managed care programs—thus excluding those types of managed care that are not risk based—because prepayment has the potential to result in underservice to enrolled members.

To identify states with Medicaid managed care programs for disabled beneficiaries, we reviewed HCFA documentation and interviewed national Medicaid experts, including officials at organizations such as the National Academy for State Health Policy and the Medicaid Working Group. From the 17 states identified as having Medicaid prepaid managed care programs for their disabled population,[19] we obtained information on a wide range of topics, including quality-monitoring activities and rate-setting methodologies. We interviewed officials in these states to obtain their views on problems they had encountered serving disabled individuals in prepaid managed care plans and ways they had gone about solving them.

On the basis of what we learned about the states as a whole, we selected three states—Arizona, Oregon, and Massachusetts—for additional study. Arizona and Oregon have relatively long-standing programs that provide a

---

[18] Under prepaid managed care, plans are at financial risk—that is, they must cover losses if the cost of providing services to enrollees exceeds the amount received in capitation fees. Conversely, they may keep the excess if the cost of providing services is less than the amount received in capitation.

[19] The 17 states are Arizona, California, Colorado, Delaware, the District of Columbia, Florida, Maryland, Massachusetts, Michigan, New Jersey, Ohio, Oregon, Pennsylvania, Tennessee, Utah, Virginia, and Wisconsin.

degree of operational experience generally not present in other states. Massachusetts has administered for almost 5 years a targeted program for severely incapacitated adults that has served as a model for other state experiments. Our work in these three states included interviewing Medicaid and other state officials, selected providers, and advocacy groups. We obtained and analyzed data provided by the three states, and where they were available, we reviewed existing federal, state, and independent studies of the programs.

During our review, we also interviewed other researchers and knowledgeable officials and reviewed available studies of managed care programs for disabled persons. We performed our work for this study between November 1995 and May 1996 in accordance with generally accepted government auditing standards.

Chapter 2

States Are Moving Toward Managed Care for Disabled Medicaid Recipients

Of the 17 states that enrolled some portion of their disabled Medicaid beneficiaries in prepaid managed care plans, enrollment ranged from less than 1 percent to all of a state's disabled beneficiaries. Six states have programs that are mandatory for some or all disabled beneficiaries. Of the remaining 11 states, 3 operate small-scale, voluntary programs focused specifically on disabled beneficiaries; 7 allow disabled beneficiaries to participate voluntarily wherever prepaid plans for the general Medicaid population are available; and 1 does both.

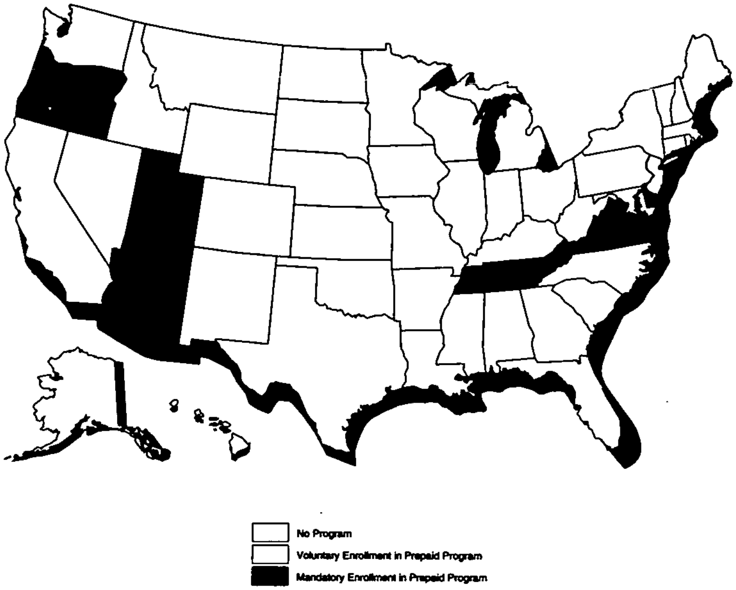
Thirteen states exclude one or both of their more vulnerable disabled populations—those in institutional care and those receiving home and community-based long-term care—from prepaid plan enrollment. However, under certain circumstances, all 17 states include one or more groups of "dually eligible" beneficiaries, who are simultaneously eligible for Medicaid and another federally funded program, such as Medicare. Coordinating enrollment and other requirements for this dually eligible group is difficult, according to state officials.

In addition to the 17 states currently enrolling disabled beneficiaries, more states have plans under way to include them in prepaid managed care. Specifically, 10 additional states have waiver proposals either approved or pending; three of these are for pilot programs to gain experience with the approach.

17 States Have Medicaid Prepaid Managed Care Programs for Disabled Beneficiaries

As of February 1996, 17 states have implemented prepaid managed care programs for disabled Medicaid beneficiaries (see fig. 2.1). Six of 17 mandate prepaid plan enrollment for most or all of their disabled Medicaid beneficiaries. Three states designed small-scale programs specifically for disabled individuals in which participation is voluntary. In seven states, disabled beneficiaries may voluntarily enroll wherever prepaid health care plans are available for the general Medicaid population. The remaining state operates both a small-scale program for disabled individuals and allows beneficiaries to enroll wherever plans are available.

Figure 2.1: States With Prepaid Managed Care Plans for Disabled Medicaid Beneficiaries, February 1996



Note: Washington, D.C. (not pictured), has implemented a targeted voluntary program.

Table 2.1 shows the available comparative data on enrollment for these programs. Limitations in reporting formats preclude comparisons for two states.[20] For the five mandatory programs with available data—Arizona, Oregon, Tennessee, Utah, and Virginia—participation ranged from 15.2 to 100 percent of all disabled Medicaid beneficiaries. Participation by eligible beneficiaries in the voluntary programs targeted exclusively to disabled individuals ranged from less than 1 percent to almost 11 percent, and participation in the remaining voluntary programs ranged from 3 to 20 percent.

Table 2.1: Enrollment of Disabled Beneficiaries in 17 State Medicaid Prepaid Managed Care Programs, February 1996

	Disabled Medicaid beneficiaries			
State	**Total disabled eligibles**	**Total enrolled in prepaid program**	**Percentage enrolled in prepaid program**	**Year enrollment by disabled began**
Mandatory programs				
Arizona	64,456	56,775	88.0[a]	1982
Delaware	12,198	N/A	N/A	1996
Oregon[b]	39,906	28,423	71.2	1995
Tennessee	138,931	138,931	100.0	1994
Utah[c]	17,155	8,158[d]	47.6	1982
Virginia	91,082	13,817[d]	15.2	1995
Voluntary programs targeted only to disabled individuals				
District of Columbia	3,200[e]	8	0.25[f]	1996
Ohio	36,000[e,g]	294	0.82[h]	1995
Wisconsin	22,041[e,i]	2,404	10.9	1994
Voluntary programs for the general Medicaid population				
California	770,067	28,262[j]	3.7	1972
Colorado	45,042	8,842	19.6	1974
Florida	N/A	N/A	N/A	1981
Maryland	83,350	10,496	12.6	1975
Michigan	234,517	42,373	18.1	1972
New Jersey	143,793	4,226	2.9	1983
Pennsylvania	247,902	50,443	20.4	1972
Voluntary program targeted to disabled individuals and voluntary program for the general Medicaid population				
Massachusetts	164,366	7,935	4.8	1992

(Table notes on next page)

---

[20] These two states—Delaware and Florida—do not disaggregate SSI and related categories to distinguish among aged, blind, and disabled beneficiaries.

Note: N/A means the state does not distinguish in enrollment and/or eligibility reports the categories of SSI and related beneficiaries that include aged and disabled.

[a] Medicaid eligible individuals not enrolled in a prepaid plan are Native Americans who live on reservations and who elected to receive care from an Indian Health Service facility.

[b] Oregon allows disabled beneficiaries, under certain conditions, to receive services in managed or nonmanaged fee-for-service settings.

[c] In 1995, the Utah program became mandatory in urban areas only. Enrollment of disabled beneficiaries in the urban areas was phased in and should be completed by July 1996.

[d] Enrollment figures include both mandatory and voluntary participants.

[e] Numbers reflect those eligible to participate in the targeted programs. See table 2.2 for more detail about which disabled beneficiaries may enroll in each program.

[f] Enrollment began in February 1996. As of March 1996, 180 children were enrolled.

[g] Program is limited to three counties.

[h] Enrollment began in one county in May 1995, another in June 1995, and the remaining county in September 1995. March enrollment for the three counties totaled 355.

[i] Program is limited to one county and enrollment is capped at 3,000, making current enrollment 80 percent of capacity.

[j] Enrollment figures are somewhat understated because data from one county do not distinguish between enrollment in prepaid and primary care case management providers.

Sources: State enrollment and eligibility reports for February 1996.

Table 2.2 describes some basic features of the four state programs designed for disabled beneficiaries. Two states—Ohio and Wisconsin—began these specialized programs in selected urban communities to gain experience before expanding their programs statewide. The District of Columbia's program is available to all eligible disabled children who live in the District. The fourth state—Massachusetts—administers a prepaid program to care for severely disabled beneficiaries but also allows disabled beneficiaries statewide to enroll in prepaid plans.[21]

---

[21] Two of the four states also have an approved or pending demonstration waiver that would require some or all disabled beneficiaries to participate in prepaid managed care. The District's program, which is an approved demonstration, is voluntary.

Table 2.2: Description of Four State Prepaid Programs Designed Specifically for Disabled Beneficiaries

State	Program name and description
District of Columbia	The Managed Care System for Disabled Special Needs Children is designed to reduce barriers to care faced by disabled children and their families. Begun in February 1996, the program contracts with a single nonprofit managed care plan to serve disabled people 22 and younger and is designed to move them, whenever possible, from institutions into community settings. Each enrolled child is assigned a primary care practitioner—usually his or her current provider—and a case manager who develops an individualized plan of care through a face-to-face assessment and helps coordinate needed medical and social services, including transportation and home adaptation. Enrollment will be phased in over 6 months with the goal of serving a total of about 3,000 within 2 years. Participation is voluntary and enrollees may change primary care practitioners at any time. One goal of the program is to build a comprehensive database profiling each enrollee to determine if caring for children with complex medical needs can be improved through managed care.
Massachusetts	Massachusetts contracts with three prepaid plans that focus on care of people with severe physical disabilities or end-stage AIDS. Combined enrollment in any given month is about 300. The program began in 1992 with a single health plan—now called the Community Medical Alliance (CMA)—which coupled primary care with enhanced home visits and case management. Severely disabled enrollees are screened for each of the following criteria: permanent triplegia or quadriplegia; a need for personal care or other equivalent assistance to maintain independent living; and one of several specified diagnoses, such as spinal cord injury, cerebral palsy, or end-stage muscular dystrophy. AIDS enrollees must meet the clinical criteria of end-stage AIDS. At CMA medical care is provided by a clinical team of physicians and nurse practitioners, with each patient assigned to a nurse practitioner. Care is provided in the most appropriate setting—most often the patient's home—as an alternative to specialty and hospital care.
Ohio	The Accessing Better Care program began enrolling physically disabled and chronically ill beneficiaries under age 65 in three metropolitan areas in 1995. It offers a flexible benefits package that includes home and community-based care as alternatives to institutional care whenever possible and currently enrolls about 300 of the 36,000 eligible beneficiaries. Each area has its own prepaid health care plan, which is a partnership between an HMO and an academic medical center. Care is delivered by an interdisciplinary care team led by a social worker or nurse case manager. Individual care plans for each enrollee are developed from initial assessments. Specialists play active roles on the care teams.
Wisconsin	Designed for disabled beneficiaries over the age of 15, I-Care began operation in 1994 and is a joint venture between a rehabilitation center and an HMO. It currently operates in one metropolitan county and will eventually serve 3,000 beneficiaries. Care coordinators assess initial medical and social needs through an in-home visit, develop an individual care plan jointly with providers and social workers, and assist beneficiaries and their families in selecting and accessing providers. Care coordinators are nurses or social workers knowledgeable about disabilities. All prepaid plan staff are trained in working with people with disabilities. Beneficiaries may select from clinic sites throughout the city. Whenever possible, enrollees' existing primary care practitioners are invited to join the provider panel. Wisconsin hopes to expand the program to two additional counties in 1997.

Six states—Arizona, Delaware, Oregon, Tennessee, Utah, and Virginia—mandate prepaid plan enrollment for some or all of their disabled beneficiaries.

- Arizona, Delaware, Oregon, and Tennessee mandate prepaid enrollment under demonstration waivers for all Medicaid beneficiaries. Oregon allows beneficiaries, in concert with their social service case workers, to select fee-for-service care (either managed—called primary care case management—or nonmanaged) when prepaid care does not best meet their health care needs. As a result, enrollment of disabled beneficiaries in Oregon is about 71 percent, compared with 100 percent in Tennessee.[22] In Arizona, Native Americans who live on reservations may elect to receive health care from either a prepaid plan or Indian Health Service facilities.

- Utah and Virginia mandate prepaid enrollment in selected areas under the program waivers they received from HCFA.

The extent to which these six states with mandatory enrollment adapt their managed care programs specifically for disabled beneficiaries is further discussed in chapters 3 and 4.

Most States Exclude the More Vulnerable From Managed Care

Medicaid covers care for two types of more severely disabled individuals—those in institutional care[23] and those receiving home and community-based long-term care.[24] People meeting these criteria are at least partially unable to care for themselves because of an injury, illness, or other disabling condition. The range of services they need extends beyond primary and acute medical care to include assistance with everyday activities, such as dressing and using the bathroom, that the individual cannot do independently because of his or her disability. Such services include personal care attendants, homemaker services, adult day care, and respite for family caregivers.

Thirteen of the 17 states exclude one or both of these vulnerable populations (see table 2.3). More specifically, 12 exclude disabled beneficiaries who reside in institutions, and 10 exclude those receiving home and community-based long-term care. Under demonstration waivers, two states—Arizona and Tennessee—mandate prepaid plan enrollment of these populations for their primary and acute care needs but provide long-term care under separate arrangements. Specifically, long-term care in Tennessee remains fee-for-service and in Arizona is coordinated by a single contractor—typically a state or county agency—for each county. In Oregon, residents of institutions for the mentally retarded and the

---

[22] Demonstration waivers allow states the flexibility to determine health care delivery systems for specified beneficiaries, including giving some a range of managed care alternatives while keeping others in fee-for-service care. Consequently, a state with "mandatory" prepaid enrollment may have certain beneficiaries in other settings. For example, Oregon designated primary care case management as an acceptable managed care alternative.

[23] Institutional care in Medicaid refers to care delivered in nursing facilities, intermediate care facilities for the mentally retarded (called ICF/MR), and, more limitedly, in institutions for those with mental diseases.

[24] Home and community-based care is made available, with HCFA approval, to Medicaid beneficiaries who, in the absence of such services, would be likely to require care in a Medicaid-covered institution.

mentally ill are not enrolled in prepaid plans, while nursing home residents are.

Table 2.3: Extent to Which 17 States Include Severely Disabled Beneficiaries in Medicaid Prepaid Care Programs, February 1996

State	Institutional populations included?[a]	Home and community-based services participants included?[b]
Mandatory programs		
Arizona	NF, ICF/MR, IMD	Yes
Delaware	No	No
Oregon	NF	Yes
Tennessee	NF, ICF/MR, IMD	Yes
Utah	No	Yes
Virginia	No	No
Voluntary programs targeted only to disabled individuals		
District of Columbia	NF, ICF/MR	No
Ohio	No	No
Wisconsin	No	No
Voluntary programs for the general Medicaid population		
California	No	No
Colorado	NF	Yes
Florida	No	No
Maryland	No	No
Michigan	No	No
New Jersey	No	No
Pennsylvania	No	Yes
Voluntary program targeted to disabled individuals and voluntary program for the general Medicaid population		
Massachusetts	No	Yes

[a] Institutionalized beneficiaries include residents of nursing facilities (NF), intermediate care facilities for the mentally retarded (ICF/MR), and institutions for mental diseases (IMD).

[b] Home and community-based services programs provide a broad range of services to beneficiaries who, in the absence of such services, would require care in Medicaid-covered institutions. Beneficiaries these programs serve include disabled people who might need care in a nursing facility and those who are developmentally disabled or mentally retarded who might need care in an ICF/MR.

Of the 17 states, only the District of Columbia includes long-term care in the set of services covered by capitation payments to health plans.[25] However, a few such programs have existed on a small scale since the 1980s, and HCFA is currently reviewing Colorado's request to implement a pilot program in one county. Integrating primary and acute care into a single prepaid contract with long-term care presents certain challenges. Among them are the lack of generally accepted standards regarding the use of various long-term care services; prepaid plans' lack of experience providing long-term care; the potential for the demise of existing community-based providers with experience in delivering such care; and the difficulty in establishing adequate rates for the combined set of services. Concerns about integrating the two types of care include the potential for medically based prepaid plans to emphasize medical technology or institutional care over the social and supportive services that many beneficiaries prefer. In addition, integration raises concerns about who should perform care needs assessments and case management services—state or prepaid plan staff—given the lack of recognized standards for appropriate long-term care and the fact that in such integrated arrangements a single provider is responsible for major portions of an individual's life needs.

Enrollment of Dually Eligible Individuals Creates Challenges

Another consideration for states with Medicaid managed care initiatives is whether to include beneficiaries who are also eligible for medical services or supplies through another federal program. For Medicaid beneficiaries, these programs fall into two categories—Medicare and title V and related school-based programs.

Medicare is a federal health insurance program that covers, among others, all people who have received Social Security disability benefits for 24 months or longer. Medicare and Medicaid provide essential and complementary services to dually eligible beneficiaries. For example, Medicare is the primary provider of inpatient and physician care, while Medicaid generally provides prescription drugs. Some estimate that about one-third of disabled Medicaid beneficiaries nationally are also covered by Medicare, but proportions will vary from state to state. For example, Oregon officials estimate that 45 percent of disabled beneficiaries are also covered by Medicare.

---

[25] Long-term care is included because the District's program is designed to help disabled children make the transition from institutional to community-based care. Arizona's long-term care program is primarily operated by state and county agencies that subcontract to separate providers for long-term care and for primary and acute care services, although the Medicaid program does not require them to do so.

Title V of the Social Security Act authorizes state programs to improve the health of mothers and children, including children with special health needs. These programs, which are limited in scope and vary among states, provide and promote state and community-based systems of services for children with special health needs and typically serve children from low- and moderate-income families. Such programs arrange for initial assessments, service plans, outpatient specialty physician services, and therapies and care coordination for children with various chronic conditions. Disabled children may receive various therapies and assistive equipment—speech therapy and wheelchairs, for example—funded from title V as well as from schools that must assure children access to certain medical services that allow them to participate in school. In many cases, these services and equipment are also covered by Medicaid.

The often conflicting or overlapping requirements of Medicaid and other programs, particularly Medicare, have been cited as a barrier to including dually eligible beneficiaries in mandatory prepaid managed care programs. In general, state officials cited the inflexibility of Medicare rules as a deterrent to developing a Medicaid prepaid program that includes those dually eligible for Medicare. Including those eligible for other programs gives rise to the need for negotiations and extensive coordination between the Medicaid staff, HCFA, and representatives from plans and other agencies serving those beneficiaries. Table 2.4 provides examples of barriers states encounter when attempting to include dually eligible beneficiaries.

Table 2.4: Examples of Barriers States Face in Including Dually Eligible Beneficiaries in Medicaid Prepaid Managed Care Programs

Program	Barrier
Medicare	Plans may be unwilling to participate in Medicaid prepaid programs if the addition of dually eligible beneficiaries threatens to raise their percentage of publicly funded enrollees above 50 percent, which would disqualify them from Medicare participation. Medicare rules regarding surrogate decisionmakers—those allowed to make decisions for people not able to make their own—are more restrictive than those of Medicaid, thereby complicating prepaid plan enrollment of dually eligible individuals and affecting who may aid them in selecting a plan. If individuals want to join the same prepaid plan for both their Medicare- and Medicaid-covered services, timing differences between the two programs may require them to remain in Medicare fee-for-service care for up to 2 months after they have enrolled in the Medicaid prepaid plan.
Title V programs	These programs for children with special health care needs are typically administered in states by departments of health, which are often separate from Medicaid agencies. Including these children requires significant interagency coordination.
School-based programs	Conflicts surrounding medical equipment such as wheelchairs or devices to help overcome communicational impairments arise when children receive services through prepaid plans and through school-based programs. In some cases, schools and plans cannot easily agree on whether the equipment is "medically" or "educationally" necessary. In others, schools or plans restrict the use of the equipment to either the classroom or the home, potentially leading to the need to duplicate services.

The nature and extent of coordination barriers between Medicare and Medicaid vary depending on the extent to which states require prepaid plan enrollment and the extent to which Medicare prepaid plans are available. Coordination issues are lessened when dually eligible beneficiaries remain in Medicare fee-for-service care and join a Medicaid prepaid plan for services not covered by Medicare. But coordination issues increase in states where beneficiaries are required to enroll in Medicaid prepaid plans and are to be "locked in" for specified periods. Chief among these are Medicare's requirement that beneficiaries are free to choose a prepaid plan or to use fee-for-service care and, when in a prepaid plan, are allowed to disenroll at will. As a result, in states restructuring their Medicaid programs under waivers, the potential benefits of coordinated care may elude Medicaid beneficiaries dually eligible for Medicare who may not be enrolled in a single managed care plan for both sets of services or have a single primary care provider—which undermines one goal of a prepaid program.

Although many of the state and federal officials we interviewed described coordination of these programs as a difficult process, most states with prepaid programs for disabled Medicaid beneficiaries are extending enrollment to the dually eligible. In all 17 states, one or both of these groups of dually eligible individuals may elect to enroll in prepaid plans (see table 2.5). For beneficiaries with Medicare eligibility, 12 states open their Medicaid prepaid programs to participation and 5 do not. Three of the 12 states reported allowing enrollment only if Medicare services were obtained in a fee-for-service setting. Another six states reported that coordination between the two programs was not a major issue because the state had no or very few Medicare prepaid plans available to beneficiaries.

Table 2.5: Extent to Which 17 States Include Dually Eligible Beneficiaries in Medicaid Prepaid Care Programs, February 1996

State	Medicare populations included?	Title V populations included?
Mandatory programs		
Arizona	Yes	Yes
Delaware	No	Yes
Oregon	Yes	Yes
Tennessee	Yes	Yes
Utah	Yes	Yes
Virginia	No	Yes
Voluntary programs targeted only to disabled individuals		
District of Columbia	No	Yes
Ohio	No	Yes
Wisconsin	Yes	Yes
Voluntary programs for the general Medicaid population		
California	Yes	Yes
Colorado	Yes	Yes
Florida	Yes	No
Maryland	Yes	Yes
Michigan	Yes	No
New Jersey	Yes	Yes
Pennsylvania	Yes	Yes
Voluntary program targeted to disabled individuals and voluntary program for the general Medicaid population		
Massachusetts	No	Yes

More States Moving Toward Including Disabled Beneficiaries

Current signs point to increasing movement in the direction of prepaid managed care for disabled beneficiaries, including greater reliance on managed care programs in which their participation is mandatory. Table 2.6 lists additional states with approved and pending demonstration waivers that include disabled beneficiaries.

Table 2.6: Status of Additional Approved and Pending Demonstration Waivers Including Disabled Beneficiaries as of February 1996

State	Date submitted	Date approved	Prepaid enrollment	Current status
Approved and implemented for groups other than disabled individuals				
Minnesota	July 1994	Apr. 1995	Four mandatory pilot programs for disabled individuals	Will enroll disabled individuals in 1997
Oklahoma	Jan. 1995	Oct. 1995	Mandatory (urban providers will be prepaid)	Will enroll disabled individuals in 1997
Vermont	Feb. 1995	July 1995	Mandatory	Will enroll disabled individuals in 1997
Approved, pending implementation				
Kentucky	June 1995	Oct. 1995	Mandatory	Implementation planning under way
Massachusetts	Apr. 1994	Apr. 1995	Mandatory	Awaiting state legislative approval
Ohio	Mar. 1994	Jan. 1995	Mandatory	Will enroll disabled at a future undesignated date
Pending				
Alabama	July 1995		Mandatory—a one-county pilot	Under HCFA review
Illinois	Sept. 1994		Mandatory (urban providers will be prepaid)	Under HCFA review
Louisiana	Jan. 1995		Mandatory	Financing plan disapproved
Missouri	June 1994		Voluntary pilot program for disabled	Under HCFA review
New York	Mar. 1995		Mandatory—to include disabled in year 2	Under HCFA review
Texas	Sept. 1995		Mandatory with managed fee-for-service option	Under HCFA review
Utah	July 1995		Mandatory if income lower than 100 percent of federal poverty level	Under HCFA review

In addition to Arizona, Delaware, Oregon, and Tennessee, which currently mandate prepaid plan enrollment for virtually all their disabled beneficiaries, six other states have received approval to require Medicaid beneficiaries, including those who are disabled, to enroll in prepaid managed care plans.[26] All but two of the six are statewide programs, and four of the six will enroll disabled beneficiaries 1 or more years after enrolling other beneficiaries. Six of the seven states seeking to include disabled beneficiaries in their prepaid programs have sought approval to require prepaid plan enrollment by most or all of their Medicaid beneficiaries, including those who are disabled. Of the seven,

---

[26] One of these six—Ohio—is currently experimenting with a voluntary targeted prepaid care program for disabled beneficiaries in three counties.

three—including Utah, which currently mandates enrollment in three urban areas—have sought approval for statewide mandatory programs. Hawaii, which currently mandates enrollment for low-income families under a demonstration waiver approved in 1993, intends to seek approval to include disabled beneficiaries in the near future. Maryland and New Jersey are currently discussing their proposals with HCFA officials.

Quality Assurance Efforts Focused on Care for Disabled Beneficiaries Are Concentrated in a Handful of States

Enrolling disabled Medicaid beneficiaries in prepaid managed care heightens the need for states to ensure the quality of care provided. Prepaid managed care, especially when participation is mandatory, diminishes beneficiaries' ability to "vote with their feet" by changing plans or physicians when they are unhappy with their care. Given disabled people's often extensive need for care, states need an adequate set of mechanisms both to address fears and uncertainties about receiving care in a managed setting and to ensure that health plans are meeting their commitments.

Important aspects of states' quality assurance activities can fall into two main categories: (1) building safeguards into the programs through adequate planning and consensus-building and (2) tailoring various aspects of the program (such as enrollment and monitoring) to meet the specific needs of disabled individuals. To date, most of the efforts have been made by five states with mandatory participation by disabled beneficiaries (Arizona, Delaware, Oregon, Utah, and Virginia) or by four states with programs targeted exclusively for disabled beneficiaries on a voluntary basis (Massachusetts, Ohio, Wisconsin, and the District of Columbia). Among other things, their initiatives include requiring plans to designate advocates or case managers for disabled beneficiaries and to include access to specific types of specialty providers, and developing encounter data and quality-of-care standards for evaluating their managed care programs for disabled beneficiaries. The remaining states (mainly those with voluntary programs for the general Medicaid population) are primarily relying on broadly scoped monitoring actions that may not be sufficient to detect problems with care provided to specialized groups such as disabled individuals.

Adequate Planning and Consensus-Building

Adequate planning and consensus among all the affected parties—health plans, disabled beneficiaries (and their advocates), and state officials—are critical for the development of and transition to an effective Medicaid managed care program, according to officials in the nine states furthest along in tailoring their programs. In particular, they stressed the need to involve beneficiaries and advocates in planning and program design. In two of the three states we visited (Massachusetts and Oregon), advocates and state officials who work with disabled beneficiaries cited the use of consensus meetings, which often involved health plan management and medical staff, as key to the smooth transition to managed care.

Oregon's experience is an example of how these consensus meetings worked. For more than a year before bringing disabled beneficiaries into managed care, Oregon's Medicaid staff held weekly meetings with health plan representatives, beneficiary representatives, and state social service agencies (from whom most disabled residents received case management services). These meetings covered such topics as building a common set of definitions for terms like "case management" and "case workers"—terms each group routinely used with different meanings. The need to arrive at such definitions was not unique to Oregon: An official in another state said coordination meetings were needed to define "disabled" because health plans anticipated diabetic or asthmatic enrollees, not quadriplegics or other individuals with medically complex needs.

Officials in the three states also noted the importance of ongoing meetings among stakeholders to address issues as they arose. They said that once the programs had been implemented, Medicaid staff met routinely with health plan management, medical directors, and advocacy and social service agency representatives to discuss such issues as rates, data reporting, and matters related to health care. These groups sometimes formed subcommittees to study specific problem areas. For example, in Oregon and Arizona the Medicaid and health plan medical directors have subcommittees to develop practice guidelines and study issues concerning disabled children. To date the state and health plan medical directors in Oregon have adopted practice guidelines for preventive care, cerebral palsy, spina bifida, and cleft palate. Guidelines for cystic fibrosis, Down's syndrome, pediatric asthma, and sickle cell disease are being developed. One of Arizona's subcommittees evaluates new treatments and technologies; it granted approval for the use of certain prescription drug treatments for cystic fibrosis and multiple sclerosis.

Tailoring Programs Specifically to Meet the Needs of Disabled Beneficiaries

The same nine states have taken action in a number of other ways to better adapt aspects of their managed care programs to address the concerns of disabled beneficiaries. These actions include addressing concerns about disabled individuals' ability to continue seeing established caregivers, helping disabled individuals and their families decide which plan to select, providing access to a range of available services, and monitoring the quality of services provided.

Resolving Concerns About Medical Necessity

Among the most important issues regarding access to services that need resolution is how the concept of "medical necessity" will be applied in prepaid care situations involving disabled enrollees. Definitions vary widely in their sensitivity to the needs of disabled individuals: Some include the need for improvement or restoration of function within a specified number of treatments or time period (often 60 days), while others include consideration of preventing the progression of adverse health conditions or the cost-effectiveness of the treatment.

The strict application of a narrow definition of medical necessity can conflict with disabled enrollees' needs, particularly in the case of services that offer little hope for improvement but can help to maintain existing quality of life. For example, people with neuromuscular disabilities may need physical therapy to prevent deterioration and reduce discomfort even when restoration or functional improvement is not possible. Conversely, state officials also pointed out that, in applying the concept of medical necessity, health plans' flexibility can provide an opportunity for them to supply services over and above those available in the fee-for-service program. For example, in one state a child received a technologically enhanced bed (not covered under the state's fee-for-service program) because health plan officials decided the bed was likely to reduce hospitalizations for pressure sores and infections.

The three states we visited address concerns about medical necessity primarily through the appeal process, giving the medical director of the Medicaid program authority to overturn health plan decisions regarding what is medically necessary for an individual recipient. However, advocates for disabled individuals said reliance on the complaint and grievance process puts an undue burden on beneficiaries because (1) the process requires a significant amount of self-advocacy on the part of beneficiaries who may not be capable of it and (2) the process can be extremely time-consuming.

Some states are beginning to include a definition of medical necessity in health plan contracts and to supplement this definition with guidance on or monitoring of its application. For example, Arizona approached the issue by including the concept of "habilitation" (the extent to which treatment helps to maintain a recipient's current ability to function) in its monitoring of health plan services. Similarly, Oregon issued guidance for health plans to use in approving various therapies and equipment emphasizing such nonmedical outcomes as enhancement of independent living.

Addressing Concerns Through Enrollment and Related Programs

Among states that offer prepaid managed care to disabled beneficiaries, only those with mandatory enrollment have significant percentages of their populations participating. The low participation in other states may reflect, among other things, concerns of disabled individuals about relying on a prepaid care system. When prepaid plan enrollment can be required of beneficiaries, state decisions about enrollment—such as who will enroll recipients, what sorts of education programs will be involved, and how beneficiaries will be assigned to a health plan if they do not choose one—become more prominent among the concerns of disabled beneficiaries, according to advocates in the states we visited. States we contacted reported using various approaches to enrollment, assignments, and exceptions to remain in the fee-for-service system.

Client Enrollment

Some states view the process of enrolling beneficiaries in Medicaid managed care programs as an important opportunity to educate and counsel beneficiaries—sometimes individually—about both managed care and the need to choose from among participating health plans. The three states we visited generally applied many of the steps they use for other beneficiaries when they enrolled disabled beneficiaries.[27] Other steps included the following:

- Oregon sends disabled beneficiaries (1) a booklet that the state developmental disabilities council created to educate beneficiaries about managed care and (2) a chart comparing the features of available health plans. The booklet contains worksheets to help beneficiaries identify their health care needs and detail their existing provider network so that they can better select an appropriate health plan.
- In Massachusetts advocates were concerned that managed care might disrupt the existing provider networks from which disabled beneficiaries receive care.[28] State staff and advocates adopted a health needs assessment that enrollment staff use to help beneficiaries select existing or other appropriate providers. The state also adopted a more flexible approach allowing specialists to serve as primary care providers for their

---

[27] Examples of such steps include sending beneficiaries materials informing them of their rights and responsibilities under managed care, sending summary information about participating health plans, and making materials prepared by health plans available for beneficiary consideration. In these three states, the materials sent to beneficiaries contained lists of participating clinics and hospitals but not individual primary care practitioners (except in one instance) or specialty care practitioners. However, in all three states, beneficiaries could contact state enrollment staff or participating health plans to obtain primary care practitioner lists.

[28] Massachusetts' program waiver requires all beneficiaries—including disabled beneficiaries—to select either a prepaid plan or a primary care case manager. In October 1995, HCFA approved state officials' request to begin assigning beneficiaries to a prepaid plan.

disabled patients and allowing beneficiaries to enroll with providers outside their geographic service areas.

Although each state makes educational materials available, state staff familiar with cognitively impaired beneficiaries in two states reported that written materials were seldom helpful to this population. Instead, for these beneficiaries, education largely occurs through the one-on-one relationships between case workers and beneficiaries and their families.

To ensure that needed equipment and supplies are provided without interruption while a beneficiary's enrollment is processed and a primary care provider is selected, Oregon also developed a process to inform the selected plan in advance about an individual's health care needs. "Continuity of care referral" forms alert prepaid plans to life-sustaining, ongoing treatment needs of individuals enrolling. Social service agency case workers, who enroll disabled beneficiaries in the prepaid plans they select, complete a form for each individual with life-sustaining needs—such as oxygen supplies—and forward it directly to the plan's care coordinator. Delaware and Virginia also require plans to either maintain existing plans of care or develop transition plans for people with ongoing care needs.

Exceptions

States with mandatory prepaid plan enrollment face decisions about whether, or if, to allow exceptions for certain beneficiaries to receive fee-for-service care. Delaware, Tennessee, Utah, and Virginia—four of the six states with mandatory programs—essentially do not allow exceptions, though individuals may receive care in a fee-for-service setting for a short time while eligibility and enrollment forms are processed. In Arizona, Native Americans living on reservations may elect not to enroll in prepaid care. Oregon allows case workers, in concert with beneficiaries and their families, to decide whether prepaid managed care is the best delivery system. Most exceptions involve an ongoing relationship with a practitioner who does not participate in any of the managed care networks, while others are for situations in which the beneficiary is involved in an ongoing treatment regime or when changing practitioners could seriously harm the individual.[29] Some exceptions are short-lived, delaying enrollment by up to 1 year; others may be permanent. Oregon Medicaid officials monitor exceptions granted by case workers to determine, among other things, whether any trends develop.

---

[29] Oregon also grants exceptions for religious or Indian heritage reasons.

Assignment

States with mandatory enrollment programs for broader segments of the population, such as low-income families, often develop systems that automatically assign beneficiaries to a health plan if they do not select one for themselves. This assignment is usually based on geographic proximity. The three states we visited each took a different approach to assigning disabled enrollees. Oregon decided against assigning disabled beneficiaries, relying instead on each social services case worker selecting a plan in consultation with beneficiaries or their families. In Arizona, severely disabled recipients who receive both acute and long-term care do not have a choice among providers because only one contract is awarded in each county. Less severely disabled beneficiaries are assigned to plans, when they do not choose from among those available, based on results of the state's competitive bidding process, with the lowest-cost plans receiving proportionately more assignments. In Massachusetts, nurse review panels analyze beneficiaries' claims histories to determine the health needs of those who do not choose health plans so that assigned plans are more likely to have the capacity to meet their needs. Enrollment staff try to contact beneficiaries after assignment to ask about their satisfaction and help them select another provider if the relationship is unsatisfactory.

Active Management of a Disabled Beneficiary's Care

Most of the nine states furthest along in tailoring their programs have also taken steps to ensure that disabled beneficiaries receive coordination of services through a process called "case management." The four small-scale programs aimed exclusively at disabled individuals have included specific requirements for case management services. Examples of such requirements are (1) coordination of a range of needed services, such as transportation, community support services, and primary and specialty care; (2) development of individual plans of care that ensure continuity and coordination of care among various clinical and nonclinical settings; and (3) stipulation that case managers be social workers or nurses with specific training in working with disabled people. In Wisconsin's program, if case managers do not perform a needs assessment within 55 days of enrollment, the beneficiary is automatically disenrolled from the program.

Among the mandatory programs, Arizona and Delaware have also taken steps regarding case management. Arizona's program for the more severely disabled requires contractors to provide case management services, although no such requirement exists for health plans serving the less disabled. Arizona requires case managers to perform a needs assessment within 15 days and complete a plan of care within 30. Failure to meet these requirements can result in a financial penalty. For the severely disabled, Arizona also established maximum ratios of 1 case manager to 40 community-based enrollees and 1 case manager to 120 institutionalized enrollees. Delaware requires plans to provide case managers for disabled children. These case managers visit children in their homes to assess the children's needs in concert with their families.

Requiring Plans to Provide Staff Advocates or Access to Specific Specialties

Several other actions are similar to case management in that they are directed at ensuring that disabled enrollees receive appropriate care. One of these actions is a requirement for a "designated advocate." Oregon and Wisconsin require health plans to have designated contact staff available for disabled enrollees and their families. These staff, called "exceptional needs care coordinators" in Oregon and "Medicaid advocates" in Wisconsin's targeted program, function as advocates for enrolled beneficiaries and must meet specific requirements for experience or training in working with those who are disabled. Oregon also created a state-level ombudsman to serve as a contact point for disabled beneficiaries and to help coordinate the activities of the plan-based care coordinators. Advocates for disabled individuals in Oregon said the coordinators perform a vital role in educating health plans on appropriate care for disabled enrollees.

Another way in which states can help ensure access to appropriate care is to require health plans to provide enrollees access to specific specialty services. For example, Utah requires prepaid plans that serve disabled children to provide timely access to pediatric subspecialty consultation and care, and rehabilitative services from professionals with pediatric training. For selected disabling conditions such as spina bifida and cerebral palsy, children must have timely access to coordinated multispecialty clinics for their disorder. Delaware requires health plans to consider disabled enrollees' requests for specialists to serve as primary care practitioners, including requests for specific specialists not affiliated with the prepaid plan. Denials of these requests may be appealed to the Medicaid agency. As of April 1996, two requests for pediatric specialists had been granted, both of which were for specialists not affiliated with the plan. Prepaid plan response to such requests is included in periodic state monitoring.

Monitoring Plans for Compliance With Contractual Requirements

Another category of quality assurance mechanisms is the compliance monitoring normally performed for all Medicaid prepaid care plans. This monitoring helps to assure the state that health plans are delivering the health services they are paid for and doing so in accordance with state and federal requirements. However, most of this monitoring activity is not specifically targeted to any eligibility group. Without some form of adjustment (a step some states are beginning to take), this monitoring will have limited effectiveness in systematically identifying problems that disabled beneficiaries may be having with their care.

Federal regulations promulgated by HCFA are the basis for much of the monitoring activity. They require, for example, that prepaid plans allow enrollees, to the extent possible, to choose their health practitioners and maintain a program that allows enrollees to voice complaints and provides for speedy resolution. States may establish performance measures to determine compliance with federal access standards. For example, as measures of access to care, states may set standards for time frames for linking enrollees with primary care practitioners, waiting times for scheduled appointments, enrollee travel time to a provider, and capacity ratios of providers to enrollees. The following are additional examples of HCFA requirements for access and quality:[30]

- Health plans must offer enrollees health services comparable to those available for non-enrolled beneficiaries in the same locale.
- Health plans may not discriminate against enrollees on the basis of their health status or need for health services.
- Health plans may not terminate enrollment because of an adverse change in the enrollees' health.
- Emergency services must be available 24 hours a day, 7 days a week.
- The state must provide for annual external reviews conducted by an independent reviewer.
- Health plans must maintain an internal quality assurance program.

States typically monitor compliance with these and other state and federal requirements through periodic (usually annual) site visits and reviews of health plan policies and procedures. Some data, such as disenrollments and complaints and grievances data, are collected and reviewed quarterly. In addition to these requirements, some states survey enrollees periodically to determine their level of satisfaction with the care received from participating plans.

Monitoring activities specifically related to disabled enrollees were limited. Of the 17 states with prepaid programs that include disabled

---

[30] Other federal requirements pertain to health maintenance plan organization and administration, data systems, financial solvency, marketing, member services, and utilization review. These requirements are specified in sec. 1903(m) of the Social Security Act and 42 C.F.R. 434.

Medicaid beneficiaries, 9 reported no specific monitoring efforts designed to assess quality of and access to care for this population.[31] For example, only those states with programs targeted specifically to disabled beneficiaries analyzed complaints and grievances by eligibility category to learn the views of disabled enrollees. Also, two states we visited reported using the results of their monitoring efforts to apply incentives and sanctions to influence health plan behavior. However, neither state had encountered treatment of disabled enrollees that would warrant the use of sanctions.

Among those nine states without specific monitoring efforts for disabled enrollees, there was acknowledgment that more needed to be done. Officials in eight of these states said more focused efforts would be needed as more disabled beneficiaries enrolled in prepaid plans. For example, these states currently rely heavily on disabled recipients' freedom to disenroll from or transfer among prepaid plans and the existence of a complaint and grievance program. However, disabled beneficiaries may choose to disenroll rather than complain about the care they receive and, even if they complain, their concerns may be masked by a low overall complaint rate for all eligibility categories unless complaints are analyzed by eligibility group. Thus, without more focused effort, such measures will not reveal systemic problems in care for disabled enrollees.

Current monitoring programs do have the potential to provide more information about care delivered to disabled beneficiaries, as the following examples indicate:

- States could extend their current efforts to assess specific aspects of health care delivery to disabled enrollees. Some states that do not assess care for disabled individuals do conduct assessments of maternal and child care. States that conduct reviews of prenatal, well child, or asthma care could require studies of care for specific disabling conditions present among the plan's enrollees. For example, a Massachusetts prepaid plan, on its own initiative, studied the management of pressure sores, a common cause of hospitalization, as an area of quality improvement. One result was the development of a variety of methods, including new screening protocols for earlier intervention and an accelerated schedule for wheelchair seating evaluations, to further improve care.

---

[31] One of these nine (Delaware) has taken specific steps to allay concerns of disabled beneficiaries about relying on prepaid plans and to help ensure access to appropriate providers, some of which have been discussed in this chapter. However, as of April 1996, the state had no specific measures to assess care received by disabled enrollees.

- Consumer surveys could include questions about eligibility status, and samples could be designed to ensure that sufficient numbers of disabled beneficiaries were included. States could also request disenrollment or utilization data reported by eligibility category to allow comparisons with other eligibility groups or across health plans. States might, as one reported, interview individuals requesting disenrollment to gather more in-depth information about the care received. In 1996, Virginia will conduct a survey of all disabled beneficiaries who disenrolled during the year.
- States have great flexibility in deciding how to structure required external reviews, which represent an opportunity for closer scrutiny of issues facing disabled individuals. Oregon, the District of Columbia, and Virginia are seeking proposals from external professional review contractors for studies specifically designed to measure the quality of care for disabled enrollees.

The steps taken to monitor plans once they are up and running need not be limited to modifying existing Medicaid oversight requirements. Targeted quality-of-care studies and quality improvement goals have been instituted by one or more of the eight states.

Targeted Quality-of-Care Studies

Arizona, the District of Columbia, Ohio, and Virginia will begin in 1996 to conduct additional quality-of-care studies focused specifically on care for disabled enrollees. Arizona's studies will include outcome measures, such as the frequency and reasons for hospitalizations and emergency room visits, rates and changes in pressure ulcers, and changes in functional abilities. Since 1990, Arizona staff have also visited a random sample of developmentally disabled beneficiaries in their homes to determine satisfaction with services and progress in fulfilling individualized plans of care developed by their health plans. The District of Columbia, Ohio, and Virginia are collecting encounter data from health plans and will evaluate care beginning in 1996 or 1997. A fourth state—Wisconsin—is scheduled to release by December 1996 an evaluation of its program conducted by independent researchers.

Quality Improvement Goals

Massachusetts uses quality improvement goals and contractor selection specifications to build health plan capacity to meet the needs of Medicaid beneficiaries. Each year, the state identifies quality improvement goals for all health plans and requires each plan to select additional goals. Twice annually, Medicaid staff meet with health plans to review progress in meeting stated goals. For each contracting cycle, the state identifies capabilities it expects successful contractors to possess. These goals and specifications have included developing capacity to serve disabled individuals. For example, one health plan elected to develop and implement a program for enrollees with human immunodeficiency virus (HIV) or AIDS to provide case management and access to specialists trained in infectious diseases. Selection criteria for 1995 required prepaid plans to demonstrate how they provided reasonable access to services for enrollees with physical and communicational disabilities as measured, in part, by enrollee satisfaction.

Programs Can Be Strengthened by Analysis of Encounter Data

Under a fee-for-service approach to Medicaid, states have ready access to data on services performed because they reimburse providers for those services. These data—called claims data in fee-for-service systems and encounter data in prepaid managed care—consist of such information as the patient's identity, type of service, date of delivery, diagnosis, and provider. In a prepaid care setting, states do not need such data for reimbursement purposes. Many plans have—and use—this information, but unless states specifically request it, the information can largely disappear from view.

This information can play an important role in quality assurance, estimations of future service use, research, and program planning. It can also play an important role in rate-setting, the subject of the next chapter. However, state experience to date shows that a substantial investment of time and effort is needed to assemble a workable encounter database, although the potential applications appear to make the effort worthwhile.

Encounter Data Have Had Limited Use to Date

When Arizona, Oregon, and Tennessee received approval to implement statewide Medicaid mandatory managed care programs, HCFA required them to collect and validate encounter data, mainly for use in independent evaluations of the programs. These states, which have had significant experience in collecting such data, all had difficulty obtaining information of sufficient quality and comprehensiveness to use in quality assurance reviews. The problems were numerous: The data were not readily available, health plans used a variety of data systems, and definitions varied from plan to plan.

- Arizona has had by far the most experience in collecting and using this information for quality assurance purposes. However, the state spent over 10 years and $30 million getting to the point that the Medicaid department could use encounter data for quality analysis.

- Oregon and Tennessee are experiencing collection and validation problems similar to those Arizona experienced initially. In each of these states, staff spent considerable time editing the data, working with health plans to overcome problems, working to resolve significant data reject and coding problems, and implementing validation strategies. In Oregon and Tennessee, relatively complete and usable data elements were not available until almost 2 years after enrollment began.[32]

State use of encounter data in quality reviews is also limited to some extent by the lack of a recognized standard for what level of care is considered appropriate for people with disabilities. In addition, quality measures for chronic and disabling conditions are just now being developed. Current federal and privately funded research and development in the field of quality analysis will provide states with more definitive criteria to use in their analyses.

Encounter Data Analysis Shows Potential in Quality Control Applications

While assembling adequate databases is difficult and expensive, the effort can yield substantial results in terms of the ability to monitor programs. The types of studies that could be conducted using person-level encounter data include tracking patterns of services by health plan or eligibility group, identifying providers serving special needs populations, and tracking the movement of high-cost patients among health plans. Encounter data could also be analyzed to reveal patterns of under- or overutilization. Although linking such patterns to quality of care in all cases is limited by the lack of recognized standards, patterns of service use can reveal access problems. For example, Arizona officials analyzed encounter data and found very low use of dental services among all beneficiaries. The access problem was resolved when state officials removed the requirement that beneficiaries receive a referral from their primary care provider before obtaining dental care.

Encounter data for Oregon's disabled enrollees are just becoming available for analysis.[33] As a result, no studies are yet under way. However, state officials listed the following as possible uses for encounter data:

---

[32] Some other states are also collecting encounter data but are not attempting to use them in this way as yet. Florida and Maryland reported collecting encounter data, but neither reported using such data, at present, in studies of care for disabled enrollees. California collects encounter data in one county. Delaware, Pennsylvania, Utah, and Virginia have either just begun or will within the next year collect such data.

[33] Enrollment by disabled beneficiaries was phased in over 9 months beginning in February 1996. As a result, the collection and availability of encounter data for disabled beneficiaries lag behind data for previously enrolled groups of beneficiaries.

comparing utilization to adopted practice guidelines to assess the extent to which they had been implemented; identifying providers serving special needs populations; identifying and tracking high-cost enrollees; identifying areas of underservice for selected services; identifying gaps in follow-up care or preventive care for selected enrollees; and analyzing enrollment to detect adverse selection by selected diagnoses.

We also identified other innovative uses of data systems for more limited quality or access reviews:

- Arizona monitors case management for certain disabled Medicaid beneficiaries through on-line systems. The state provides case managers with the terminals and software with which they record the individuals' plan of care and progress in meeting stated goals. This information is then transmitted to the Medicaid department for immediatiate review.
- The contracting health plan in the District of Columbia also plans to use an on-line system for its own and the District's monitoring of care for enrollees. For case managers providing 24-hour medical access to beneficiaries and their families, the system gives access to care plans, service authorizations, and even scanned-in photographs of the children.
- In Massachusetts, the Medicaid department compared managed care aggregated utilization data with fee-for-service claims data to determine whether mental health services were underutilized. The state took immediate action to work with prepaid plans that needed to correct utilization problems.

Risk-Adjusted Rates and Risk-Sharing Can Help Reduce Incentives to Underserve Disabled Beneficiaries

Adequate quality-of-care safeguards provide some protection against the potential risks of prepaid managed care. Paying health plans a capitation rate in advance to provide enrollees a set of services creates an incentive to improve efficiency by eliminating unnecessary services. However, it simultaneously creates certain risks. First is a risk of underservice, because plans can profit by reducing the number or quality of beneficial services. Second is the risk that when the same capitation rate is paid for enrollees with different health care needs, plans will seek to enroll the healthier, less expensive individuals. These risks may be greater when plans feel financial pressure from actual or potential losses from serving enrollees with extreme needs.

States are examining ways to reduce these incentives and pressures in prepaid care plans that have a disproportionate share of beneficiaries with high-cost medical needs, such as severely disabled people. States' efforts have been of three main types:

- Using risk-adjusted capitation rates to more closely match the reimbursement rates with anticipated costs of treating individual recipients.
- Sharing financial risk by providing retrospective adjustments (called "reinsurance") to reimburse plans for losses resulting from very high-cost individuals or disproportionate numbers of enrollees with above-average costs.
- Establishing funding agreements with "risk corridors" that reimburse plans for a portion of losses but also require plans to return part of the profits exceeding a specified level.

For the 17 states we contacted with managed care programs for disabled beneficiaries, most state activity to date has centered on reinsurance. Initiatives to establish risk-adjusted rates for disabled enrollees or to set up risk corridors in funding agreements are fewer in number and have much shorter track records. Risk-adjusted rates—currently implemented in only two states—are seen as potentially beneficial by many states but also as administratively difficult to develop and maintain. As the only mechanism that specifically limits health plan profits, risk corridors appear to have the greatest potential for reducing plans' incentives to underserve or to enroll only the healthier beneficiaries. To date, five states have taken steps to build risk corridors into their payments to plans.

Traditional Rate-Setting Approach Does Not Address Negative Incentives and Pressures

In setting capitation rates, states make an effort to account for differences in expected costs for broad categories of beneficiaries. To do this, they frequently divide the eligible population into subgroups, or cells, of individuals with similar characteristics. Of the 17 states we contacted, 16 established rate cells according to Medicaid eligibility category, such as all disabled people or all children in AFDC-eligible families, with some adjustment for age or the geographic area in which the beneficiaries reside.[34]

Setting capitation rates in this way meets HCFA requirements and provides appropriate payments to plans as long as each plan's enrollment mix of beneficiaries with complex health care needs is comparable with the mix of the population used to set the rates.[35] The money saved serving enrollees with lower-than-average costs pays the cost of serving enrollees with higher-than-average costs. However, plans may not enroll disabled people with health care needs comparable with those included in setting the rates. While some disabled enrollees may require little medical treatment, others may have disabilities, such as quadriplegia, that require extensive treatment. The identifiability of such groups and the high costs associated with their care heighten the incentives for health care plans to avoid enrolling such individuals.

In most state programs, the rate-setting methods do not take into account the cost variation associated with different types of disabling conditions. Researchers have identified significant variation in medical costs within different subcategories of conditions. For example, using 1992 fee-for-service claims data divided along clinical diagnoses, researchers found average annual costs ranging from nothing (for the 5 percent of the disabled population that had no medical claims during the year) to $35,000 per year in one state for an individual diagnosed with quadriplegia. Similarly Oregon found tremendous variation in 1993 health care costs among its 199 highest-cost children. The 6-month group average was $21,472, but amounts varied from a high of $410,420 to a low of $5,014. In

---

[34] For example, Oregon's 1996 (January through September) average rate for categorically eligible children in families under the federal poverty level is $126.15 per month, while its average rate for blind or disabled individuals who have no Medicare coverage is $521.81 per month.

[35] Richard Kronick, Zhiyuan Zhou, and Tony Dreyfus, "Making Risk Adjustment Work for Everyone," Inquiry, Vol. 32 (Spring 1995).

1995, Oregon's average 6-month capitation rate for disabled individuals in the cell that includes these children was $3,023.[36]

High-Cost Cases Strengthen Pressure to Seek Healthier Enrollees

With such a broad range of costs within the category of disabled enrollees, a health plan being paid on the basis of average costs may make profits or experience losses unrelated to its ability to provide high-quality health care services efficiently. Instead, these profits or losses may be a function of how many high-cost cases it does or does not enroll. A health plan with a disproportionate number of high-cost cases that result in unanticipated losses is said to be experiencing "adverse selection," while a plan with few high-cost cases is said to be experiencing "favorable selection."

The greater the difference between the high- and low-cost recipients in each cell, the greater the pressure on plans to avoid enrolling high-cost recipients or to underserve the high-cost beneficiaries who do enroll. Favorable selection may happen unintentionally in that, as research suggests, some people—often those with few health care needs—may be more prone to select prepaid care when given the option. But, plans can also avoid enrolling high-cost members by using a variety of methods that may be difficult for states to detect.

- Manipulating the panel of providers. Health plans can avoid high-cost recipients by dropping providers that attract high-cost patients. For example, a former health plan official told us that the health plan she worked for identified a specific provider who was responsible in large part for the plan's attracting a significant number of enrollees with AIDS—a condition that frequently requires extensive and expensive treatment, especially in its later stages. This plan dropped the provider from its panel in favor of an AIDS treatment clinic and saw its AIDS caseload decrease. The decision to drop the provider may have been for other reasons, in that by adding the clinic and dropping the individual provider, the health plan may have improved its capacity to treat people with AIDS and the quality of care they would receive. The outcome demonstrates, however, recipients' attachment to specific providers and health plans' ability to (1) identify specific providers as magnets for high-cost recipients and (2) reduce the cost to treat these recipients by dropping or replacing certain providers.
- Limiting access to information about specialty providers. Health plans can also make it difficult for prospective enrollees to find out which specialty

---

[36] Because (1) Oregon lacked a systematic approach to case management for these children and (2) plans have limited flexibility in providing low-cost in-home care, the most "medically fragile" of these children were taken out of prepaid care and are being served on a fee-for-service basis with case management by state staff.

providers are available through the plan. In one state we studied, the state and health plans initially resisted distributing a handbook produced by an advocacy group designed to help disabled Medicaid recipients select a health plan that could best meet his or her particular needs. The booklet contained a worksheet for individuals to detail their specialty care requirements. The state and health plans were concerned about the possibility of adverse selection and felt that, without this information, the high-cost cases would be more evenly distributed among the various health plans.

- Using marketing efforts to discourage enrollment. Some states have allowed plans to conduct direct marketing as a way of enrolling beneficiaries in managed care. However, through direct marketing, health plans can also attempt to deliberately influence the distribution of high-cost enrollees. For example, they may seek information on a person's health status or discourage—or not aggressively market to—those likely to have more expensive needs. Consequently, several of the states in our review prohibited or severely limited the amount and content of marketing by health plans.
- Remaining silent about new treatment approaches. The wide gap between the relatively healthy and the sick within a rate cell also discourages the dissemination of information about health plans that have found innovative and successful ways to treat enrollees with difficult conditions. One health plan official told us that when the plan develops innovative and successful ways to treat the chronically ill, it does not advertise this fact because the resulting increase in enrollment of chronically ill individuals could be financially devastating. This health plan had success in managing asthma, and as word of its success spread, the number of asthmatics enrolling in the plan increased dramatically. This increase had such a negative financial impact on the health plan that it asked the state to cap its enrollment to prevent additional high-cost recipients from enrolling. When the incentive of health plans to develop innovative treatments decreases, disabled individuals are adversely affected in that they may miss out on new and effective treatments.

Determining whether a health plan is facing adverse selection goes beyond reviewing the plan's financial statements to see if there is a profit or loss. Health plans that do poorly managing care may lose money and blame it on adverse selection even though they may in fact be the beneficiary of favorable selection. Alternatively, plans actually experiencing adverse selection may limit services to such an extent they are still able to show a profit. Medicaid officials told us it is not uncommon for all participating health plans to describe themselves as victims of adverse selection, an impossible situation. However, these states had limited ability to verify or refute such claims with any certainty.

States Could Experience Adverse Selection and Lose Money With Managed Care

Health plans are not the only players in the Medicaid managed care marketplace that can face adverse selection and financial risks. When prepaid managed care plan enrollment is voluntary (as it is in 11 of the 17 states now using prepaid care for some or all of their disabled beneficiaries), the state may experience adverse selection. Specifically, where participation is voluntary, beneficiaries with relatively few health care needs (who may have few, if any, existing relationships with specialists) may choose prepaid care, while beneficiaries needing more expensive care (who may have long-standing relationships with specific providers) may choose to remain in fee-for-service care. When enrollment is mandatory but exceptions are allowed, a state may similarly face adverse selection.

Enrollment patterns in which the users of the most expensive medical services are in fee-for-service care and the relatively healthy in prepaid managed care are not problematic if the rate the state pays the health plans is adequately adjusted for the health status of the enrollees. However, in many cases, the rates paid to health plans are based on the average cost of providing care to an entire eligibility category and may not appropriately account for those that do not elect prepaid care. Consequently, the state pays the full cost of treating the expensive beneficiaries through fee-for-service care and too high a rate for the lower-cost health plan members. This problem may be compounded in that it is likely that future capitation rates would be based on the costs of serving those remaining in fee-for-service care—individuals who are likely to be less healthy and consequently more costly.

Just as it is difficult to tell if a health plan is experiencing adverse selection, it is very difficult to determine whether a state is experiencing adverse selection. An Oregon Medicaid official suspects that the state's enrollment exemption process for disabled individuals, which allows case workers to determine if prepaid managed care is appropriate for individual beneficiaries, may be resulting in adverse selection for the state.

Risk Adjustment and Reinsurance Have Some Impact on Incentives for Favorable Selection or Underservice

To address the concerns associated with adverse and favorable selection, some states are beginning to experiment with risk-adjusted methods for setting capitation rates. Risk adjustment is an attempt to match the rates paid to health plans with the expected costs of providing appropriate services to individual recipients. It essentially groups beneficiaries according to expected future expense and narrows the gap between the highest-and lowest-cost individuals in any given rate cell. This reduces the payoff for selecting only the healthiest recipients and provides better assurance that the state is not paying too much for individuals who are relatively healthy or too little for individuals who need such complex and expensive care that health plans are at best unwilling to attract and at worst unwilling or unable to accommodate them.

However, the actual application of risk-adjustment methods to the development of capitation rates for disabled Medicaid beneficiaries is very limited.[37] To date, only two states (Massachusetts and Ohio) have implemented any risk-adjustment methods, and only one other state (Missouri) has active plans to do so. Other states told us that risk adjustment was too administratively difficult to implement and that they looked to reinsurance to protect plans that experience adverse selection. Reinsurance does not, however, affect plans' incentive to seek favorable selection.

Risk Adjustment Is Largely Untested for Disabled Enrollees

The three states experimenting with risk-adjusted rates have based their adjustments on a beneficiary's prior utilization of medical services or a beneficiary's clinical diagnosis. Researchers point out that such measures may better predict future costs since disabled individuals, compared with the population as a whole, have a higher percentage of their health care costs related to chronic (recurring or consistent) conditions than to acute (random) conditions. Still, for risk-adjustment methods to be useful, attention must be paid to whether the predictive measures are sufficiently reliable and administratively feasible to collect.

Risk Adjustment Using Prior Utilization Rates

Utilization-based risk adjustment attempts to predict a person's future health care costs based on a measure of prior use, such as the costs of services or the number of hospital days used in a previous period. For example, a health plan could be paid a higher-than-average amount if the

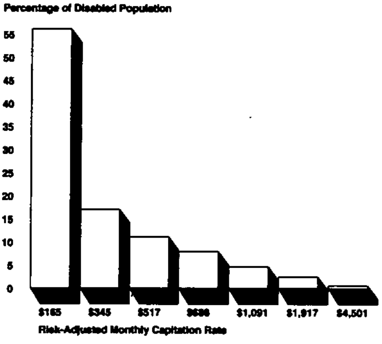
---

[37] To date, research on risk-adjustment mechanisms has concentrated more extensively on the Medicare population. We examined risk-adjustment mechanisms among the Medicare population in two reports, Medicare: Changes to HMO Rate Setting Method Are Needed to Reduce Program Costs (GAO/HEHS-94-119, Sept. 2, 1994) and Medicare Managed Care: Growing Enrollment Adds Urgency to Fixing HMO Payment Problem (GAO/HEHS-96-21, Nov. 8, 1995).

person spent several days in the hospital in the last year or a lower-than-average rate if the person spent no time in the hospital or did not visit the doctor in the last year.

To set capitation rates for its disabled population, Ohio is moving forward with a pilot project that uses a beneficiary's prior utilization (measured in dollars) in the fee-for-service system. This program, called Accessing Better Care, uses eight rate cells for the disabled population. Seven of the cells are based on prior expenditures, and the eighth is for newly eligible beneficiaries. Monthly capitation rates range from $165 (for beneficiaries with prior annual costs of $1,000 or less) to $4,501 (for beneficiaries with prior annual costs of $50,000 or more). Figure 4.1 shows how Ohio's disabled beneficiaries are distributed among the seven prior-expenditure categories.[38] More than half of all disabled beneficiaries are in the lowest-cost cell.

Figure 4.1: Ohio's Risk-Adjusted Capitation Rates and the Percentage of Disabled Population at Each Rate



Risk Adjustment Using Clinical Diagnosis

Another approach predicts future health care costs using beneficiaries' individual clinical diagnoses. Various methods to identify or classify diagnoses can be used, employing inpatient data, outpatient data, or both.

---

[38] The distribution is an average from 1991 and 1992 fee-for-service data.

Some methods rely on an individual's primary diagnosis, and others incorporate measures of the severity of the primary diagnosis as well as the existence of secondary diagnoses of conditions that may aggravate the individual's health status.

Massachusetts is one of two states working with a diagnosis-based approach. It has identified a few disabling conditions that warrant higher rates and, as a result, has created a three-celled, diagnosis-based risk-adjustment system for its disabled Medicaid population. Severely disabled beneficiaries and those with end-stage AIDS (in both cases meeting clinical criteria detailed by the state and receiving an enhanced benefits package) have capitation rates of about $1,500 and $4,400 per month, respectively, compared with about $500 per month for beneficiaries in the general disabled category.

Missouri is currently developing a diagnosis-based methodology as part of a prepaid care program for disabled Medicaid beneficiaries scheduled to begin in 1997. Their methodology adjusts the capitation rate paid for an individual recipient according to both the type of diagnosis and its severity. The state identified approximately 400 distinct diagnoses and computed a rate-adjustment factor for each. The rate for an individual is the sum of the adjustment factors for each of the individual's diagnoses. The methodology accounts for multiple diagnoses: the capitation rate for an individual with diagnoses of muscular dystrophy and mild mental retardation would be higher than the rate for a mildly retarded individual with no additional disabling diagnoses. Table 4.1 shows an initial estimate of the resulting base rate along with a sample of the diagnoses identified and the associated capitation adjustment.

Table 4.1: Missouri Sample Diagnostic Categories and Rate Adjustments

Base rate, per month: $143

Sample diagnostic categories	**Adjustment**
Hemophilia, other clotting factors	$1,495
Cystic fibrosis, respiratory failure	1,108
Quadriplegia	517
Muscular dystrophy/paraplegia	263
Mild and moderate mental retardation	74

Note: Rate adjustments are additive. For example, the rate for an individual with muscular dystrophy and mild mental retardation would be $480 per month ($143 for the base rate plus $263 for muscular dystrophy and $74 for mild mental retardation).

Source: Missouri Division of Medical Services.

Risk-Adjustment Methods Must Be Accurate, Free From Manipulation, and Workable

Although risk-adjustment mechanisms are designed primarily to prevent adverse and favorable selection, implementing a risk-adjustment scheme involves a number of other considerations. Risk-adjustment methodologies must not only be reasonable predictors of future health care costs, they must also be relatively insulated from manipulation by health plans or providers, and they must be feasible in terms of administrative and data requirements.

To prevent adverse or favorable selection, a risk-adjustment mechanism must be able to predict health care costs. Researchers have demonstrated that prior utilization and diagnosis-based methodologies can both have predictive power superior to that of rates based on eligibility category. Some prior utilization models are able to explain nearly 40 percent of the variation in health care costs for disabled individuals, and diagnosis-based models have been able to explain about 25 percent. However, even the best predictors of health care costs explain less than half the variation in costs of providing care. Plans then still have an incentive to avoid the higher-cost members of a rate cell.

The basis selected for risk adjustment can affect the behavior of health plans.

- With utilization models that use cost as a measure, health plans have less of an incentive to hold down costs because less efficient health plans may be rewarded with higher capitation rates as participants are characterized as high use. Conversely, a plan that manages its enrollees' care very efficiently may be penalized with lower capitation rates in the future. Moreover, a prior utilization method based on the number of hospital admissions affects health plan behavior in a different way than one based on the number of days an individual spends in the hospital. In both cases, the health plan could manipulate the measure affecting future rates without necessarily losing much in terms of efficiency.[39]
- With diagnosis-based risk-adjustment methods, "upcoding" exists in which providers and plans record the most severe diagnosis—the diagnosis associated with the greatest capitation adjustment—of those available for an individual's symptoms. The use of multiple diagnoses as factors in the rate-setting methodology creates a situation in which providers could record unwarranted diagnoses to raise future capitation rates.

---

[39] To account for the effects of adverse selection, some states are considering making retrospective adjustments to capitation rates based on utilization. Such an adjustment can ease the effects of a large number of high-cost cases, but it may also strengthen the incentive for health plans to act inefficiently. With a retrospective adjustment, plans would be rewarded for their inefficient behavior in the current year, rather than having to wait for higher rates in the future.

To be useful, risk-adjustment methodologies must also have feasible administrative and data requirements. Measures of health status, collected through surveys, may help predict the need for future health care but may be too administratively burdensome to be practical. Risk-adjustment methods based on information about the use of services are more practical. However, while such information was routinely available in fee-for-service claims, states need a new source, such as encounter data, to classify individuals enrolling in health plans.

The lack of fee-for-service data is not a problem limited to states that adjust their capitation rates by risk. Any state that moves most or all of its Medicaid population into managed care will find that prior rate-setting methods based on averaging fee-for-service claims will be unsuitable. While rates calculated using older fee-for-service data might be trended forward using any of a variety of factors, over time such trending may cause rates to be unrepresentative of the health care services being used. To address these difficulties, some states are using or evaluating individual-level encounter data as a basis from which they can generate capitation rates in the future.

Reinsurance Relieves Financial Pressure on Plans but Not Negative Incentives

State officials we contacted recognized the benefits of prospectively risk-adjusting capitation rates but—with the exceptions of Ohio, Massachusetts, and Missouri—were reluctant to do so in their programs because they felt it was too difficult administratively. Instead, officials rely on reinsurance to decrease the pressure on health plans serving high-cost individuals. With reinsurance, the reinsurer (sometimes the state) protects health plans against adverse selection or unexpectedly high-cost cases. To obtain coverage, the plan pays a reinsurance premium.

Reinsurance programs come in many forms. Most programs involve a reinsurance threshold, or deductible, with health plans being responsible for all the costs of serving a group or an individual up to that amount. Once the threshold is met, the state shares the cost of treating the group or individual with the health plan. Table 4.2 shows the range of reinsurance options Oregon offers in its current health plan contracts.

Table 4.2: Oregon's Reinsurance Levels and Rates, 1995-97

Annual deductible per person before state will participate	Percentage of liability over the deductible to be paid by the plan	Reinsurance premium as a percentage of capitation
$10,000	5	29.9
15,000	10	19.7
30,000	20	9.3
50,000	20	4.1

Source: Oregon Office of Medical Assistance Programs.

State Medicaid officials told us that, by protecting health plans from extraordinary costs, reinsurance also helps build health plan capacity. For example, new health plans and plans with small enrollments need time to absorb spikes in service costs and the cash flow fluctuations inherent in prepaid managed care. With reinsurance available, these plans can participate and compete in the programs.

While reinsurance relieves some pressure on health plans faced with expensive cases, it does not remove the negative incentives discussed earlier. Plans still may benefit from enrolling the healthiest eligibles or from underserving the high-cost cases that do enroll. Reinsurance compensates plans only after they lose money on a case or on all their enrollees. While reinsurance may relieve some pressure on plans facing losses, it may not affect the incentives plans create with individual providers to limit services. These incentives set out in the provider's contract may not automatically adjust when the costs of a provider's patient reach the reinsurance threshold.

In some areas, Medicaid managed care reinsurance may not be readily available in the private market and may not be available at all for small health plans. Consequently, state Medicaid agencies become de facto insurance companies with the associated risk and resource requirements. As reinsurers, states face the challenge of setting appropriate reinsurance premiums—inappropriate premiums could lead either to plans paying too much, and thus increasing the pressure to underserve, or plans paying too little, which leaves the state in a money-losing position.

Risk Corridors Have Greatest Impact on Negative Financial Incentives

Five states—the District of Columbia, Massachusetts, Ohio, Utah, and Wisconsin—are building risk corridors into their contracts to help mitigate the potentially negative incentives affecting health plans' treatment of disabled enrollees.[40] Unlike reinsurance, risk corridors work in two directions, sharing both losses and profits with health plans below and above preestablished ratios.

As the only mechanism that specifically limits health plan profits, risk corridors have the greatest impact on incentives facing health plans to either reach for the lowest-cost recipients in any given rate cell or to underserve the high-cost enrollees they cannot avoid. The point at which profit and loss sharing begins—the width of the risk corridor—varies from state to state, as does the degree to which profits and losses are shared. Table 4.3 shows the risk corridor arrangement Massachusetts has in its current contract with a plan that provides prepaid care for the severely disabled.

Table 4.3: Massachusetts Risk Corridors for Plan Providing Prepaid Care to the Severely Disabled

Situation at end of contract period	Outcome
Plan has medical expenditures totaling more than 10% below capitation payments	The difference above 10% reverts to the state
Plan has medical expenditures between 0 and 10% below capitation payments	Plan keeps 40% of the difference; 60% reverts to the state
Plan has medical expenditures between 0 and 10% above capitation payments	State pays 50% of the difference
Plan has medical expenditures totaling more than 10% above capitation payments	State pays 75% of the difference

Source: Massachusetts Executive Office of Health and Human Services.

By reducing the potential for profits, the state is affecting implicit health plan calculations regarding the costs and benefits of restricting services. When $1 saved from restricting service translates to $1 of profit, a health plan may be willing to risk losing enrollees who are dissatisfied with health plan service. With risk corridors, however, $1 saved may only translate to 30 or 40 cents in profit, reducing the benefit side of the equation. Because health plans understand how risk corridor arrangements operate before entering into Medicaid prepaid care agreements, corridors also have the unique feature of being a retrospective adjustment with a prospective impact. Risk corridors and their profit limits may affect health plan risk arrangements established with individual

---

[40] In addition to these five states, Tennessee has limited profits for certain of its managed care organizations to 10 percent but plans to discontinue the practice in December 1996.

providers in a way that reinsurance does not. In their provider contracts, plans may limit the incentives to reduce services when their profits will be limited.

Observations, Conclusions, and Comments

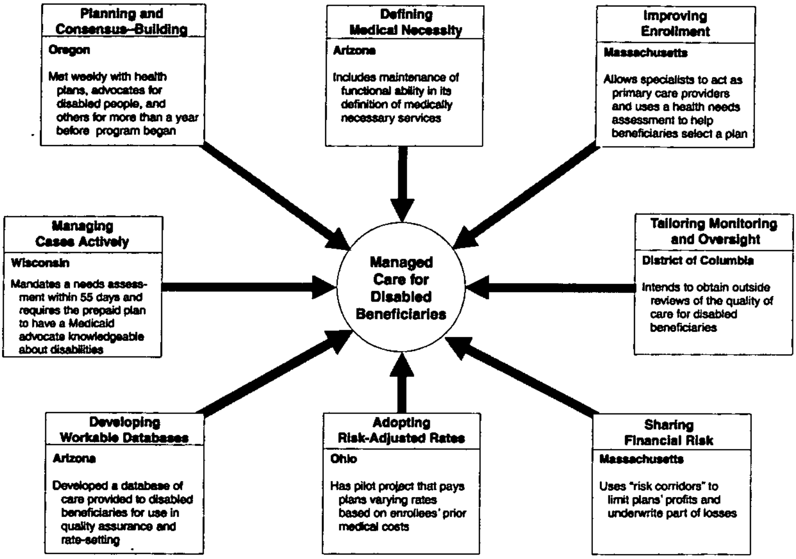
Enrolling disabled beneficiaries in prepaid managed care is a growing trend in Medicaid. Moreover, because much of the proposed expansion is directed toward mandatory managed care, the future expansion of prepaid care for disabled Medicaid beneficiaries appears likely to be even more sweeping in its effect. Thus far, two-thirds of the states providing prepaid care for disabled beneficiaries offer it on a voluntary basis. By contrast, 12 of the 13 states with newly approved or pending Medicaid managed care waivers intend to mandate participation by disabled beneficiaries.

The implications of this shift toward mandatory programs are substantial. Prepaid care has operated in both the public and private arenas as a system based on averages. For example, populationwide averages drive the expectations of what services should be provided and how much they will be used. Likewise, prepaid rates are calculated on average costs, and quality has been monitored, in part, using aggregated average utilization rates. To adequately safeguard the interests of disabled beneficiaries, however, state programs must recognize that these beneficiaries are quite distinct from the general Medicaid population. Not only are their health needs greater than those of the general population, but included among them are a small number of highly vulnerable individuals whose needs are extensive and critical to the prevention of death or further disability. Not addressing these differences heightens the risk that prepaid care plans will try to hold down their costs by (1) discouraging enrollment from high-cost segments of the disabled population or (2) inadequately serving those high-cost beneficiaries they cannot avoid.

Thus far, actions at the state level do not reflect a widespread acknowledgment of the changes in approach that should occur when applying managed care to disabled beneficiaries rather than the general population. In most states, the level of effort to anticipate and accommodate the needs of the various stakeholder groups (disabled individuals and their advocates, the health care plans, and the government) in their current programs has been limited largely because participation in these programs has been voluntary. The efforts have tended to be most extensive in those few states that have already put mandatory or targeted programs in place.

No clear blueprint has yet emerged for how to incorporate disabled beneficiaries into Medicaid managed care plans. The limited efforts to date have not been in place long enough to allow definitive conclusions about how effective they are. At this relatively early stage, however, several key areas are emerging that merit consideration by all parties seeking to develop effective prepaid programs. These key areas, and examples of state actions to address them, are illustrated in figure 5.1.

Figure 5.1: Key Approaches for Including Disabled Beneficiaries In Medicaid Managed Care and Examples of State Initiatives



Planning and Consensus–Building
Oregon
Met weekly with health plans, advocates for disabled people, and others for more than a year before program began

Defining Medical Necessity
Arizona
Includes maintenance of functional ability in its definition of medically necessary services

Improving Enrollment
Massachusetts
Allows specialists to act as primary care providers and uses a health needs assessment to help beneficiaries select a plan

Managing Cases Actively
Wisconsin
Mandates a needs assessment within 55 days and requires the prepaid plan to have a Medicaid advocate knowledgeable about disabilities

Tailoring Monitoring and Oversight
District of Columbia
Intends to obtain outside reviews of the quality of care for disabled beneficiaries

Developing Workable Databases
Arizona
Developed a database of care provided to disabled beneficiaries for use in quality assurance and rate-setting

Adopting Risk-Adjusted Rates
Ohio
Has pilot project that pays plans varying rates based on enrollees' prior medical costs

Sharing Financial Risk
Massachusetts
Uses "risk corridors" to limit plans' profits and underwrite part of losses

To date, few states have significant, long-term experience with programs that mandate enrollment by their disabled population. Even fairly extensive experience with voluntary programs may not fully prepare health plans and state officials if, as research suggests, those who select prepaid care in voluntary situations tend to be healthier than those who do not. A state may find it useful to develop and operate a targeted or relatively small-scale program before moving to any large-scale effort to mandate the enrollment of disabled beneficiaries. Small-scale programs would allow health plans, beneficiaries, and state staff to gain experience with meeting the diverse and complex needs of disabled individuals in a prepaid setting.

For states that elect to move immediately into a large-scale program, the areas shown in figure 5.1 are even more critical. Adequate preparation, consensus-building, and program safeguards assume greater significance when substantial numbers of people are being added, particularly if their ability to change plans readily is limited.

Understanding the various approaches currently being tried will provide states with a good starting point for planning their own efforts. Making prepaid managed care work for disabled individuals will be achieved only through the combined and continuing efforts of states, health plans, and beneficiaries and their advocates.

Agency and Other Comments

We provided a draft of this report to the Administrator, HCFA. The draft report was reviewed by officials in HCFA's Office of Managed Care, Office of Research and Demonstrations, and the Medicaid Bureau. HCFA officials had no technical or other comments on the report draft. In addition, we provided relevant sections of the draft report to Medicaid staff from the 17 states in our report. All but one state responded with comments, generally agreeing with the accuracy of the information. Officials in Arizona commented that the draft report seemed to suggest prepaid managed care is not suitable for people with disabilities. We believe, instead, that given the limited state and health plan experience with serving disabled individuals in prepaid care and the medical complexity of their health care needs, careful attention is required in designing, implementing, and monitoring programs for this population.

In addition to requesting comments from HCFA and state agencies, we provided the draft report to several independent researchers from the National Academy for State Health Policy, the Medicaid Working Group, MEDSTAT, and Fox Health Policy Consultants. These researchers generally agreed with the accuracy and comprehensiveness of our presentation of the issues and programs. We incorporated technical and clarifying comments from states and external researchers as appropriate.

Appendix I

Major Contributors to This Report

Kathryn G. Allen, Assistant Director, (202) 512-7059
Cheryl A. Williams, Evaluator-in-Charge, (503) 235-8451
Deborah A. Signer
Stanley G. Stenerson
Mark D. Ulanowicz

United States General Accounting Office

GAO

Report to Ranking Minority Member,
Committee on Commerce, House of
Representatives

May 1997

MEDICAID MANAGED CARE

Challenge of Holding Plans Accountable Requires Greater State Effort

GAO

United States
General Accounting Office
Washington, D.C. 20548

Health, Education, and
Human Services Division

B-270335

May 16, 1997

The Honorable John D. Dingell
Ranking Minority Member
Committee on Commerce
House of Representatives

Dear Mr. Dingell:

Over the past decade, Medicaid expenditures have soared. By fiscal year 1996, they reached $160 billion—nearly quadrupling fiscal year 1986 expenditures. Although the annual growth rate abated significantly in 1996, Medicaid expenditures continue to exert strong pressure on federal and state budgets. To help bring these costs under control, states increasingly are mandating significant numbers of their Medicaid population to enroll in managed care programs. By emphasizing primary and preventive care and treatment, it is hoped that managed care will improve beneficiary health care while curbing health care costs.

As of June 1996, about 11 million Medicaid beneficiaries were enrolled in "capitated" managed care programs.[1] Under a capitated managed care model, states contract with managed care plans, such as health maintenance organizations (HMO), and pay them a monthly, or capitated, fee per Medicaid enrollee to provide most medical services—which are coordinated through primary care physicians. This model, with its fixed prospective payment for a package of services, creates an incentive for plans to provide preventive and primary care and to ensure that only necessary medical services are provided. However, managed care also can create an incentive to underserve or even deny beneficiaries access to needed care since plans and, in some cases, providers can profit from not delivering services. Moreover, Medicaid beneficiaries required to enroll in managed care may find it difficult to seek alternative care if they find that plan providers fail to meet their needs.

Because of your concern about these issues, we reviewed state efforts to hold managed care plans accountable for meeting Medicaid program goals and for providing beneficiaries enrolled in capitated managed care plans the care they need. As agreed with your office, we focused our study on the difficulties that purchasers, including states, have in monitoring

---

[1] Based on the most current data available from the Health Care Financing Administration (HCFA) on managed care enrollment. Another 4 million individuals were enrolled in noncapitated managed care programs. Of the total 15 million managed care enrollees, about 2 million were enrolled in more than one plan, according to HCFA.

managed care programs and on state efforts to (1) ensure Medicaid beneficiaries have access to appropriate providers, (2) assess the adequacy of medical care provided through contracted plans, and (3) determine beneficiary satisfaction with plan performance.

To understand the types of issues states face in ensuring accountability and quality in their capitated Medicaid managed care programs and the steps taken to address these issues, we visited four states—Arizona, Pennsylvania, Tennessee, and Wisconsin. At the time of our review, these four states collectively had almost 1.9 million Medicaid beneficiaries enrolled in their managed care programs. To analyze and illustrate state actions, we focused the scope of our work on 10 core accountability measures or processes deemed essential by HCFA and experts we contacted.[2] We reviewed these states' contracts with managed care plans and other plan requirements, as well as their efforts to monitor plan performance. Appendix I provides more detailed information on our scope and methodology.

Results in Brief

Ensuring that managed care plans provide enrollees the care that they need is a formidable task for private and public purchasers alike. In establishing their managed care programs, purchasers can require contracted plans to meet certain conditions—such as maintaining adequate provider networks and complying with data collection requirements—that help to hold them accountable for providing enrollees with appropriate care. However, establishing criteria for these conditions and monitoring plan compliance are often difficult because of a lack of population-based standards or benchmarks for what constitutes appropriate care or expected outcomes. In addition, individual-level data on patient care, such as those that are generated in a claims-based fee-for-service system, are not readily available. For states, establishing standards of care and tapping into alternative information sources on service utilization to assess the care that Medicaid beneficiaries receive can be a challenge. The four states that we visited—Arizona, Pennsylvania, Tennessee, and Wisconsin—have built access and data collection requirements into their contracts with managed care plans. We found, however, that plan compliance with the requirements we reviewed does not necessarily ensure that beneficiaries are receiving the care that they need.

---

[2] Our work did not include a complete assessment of each state's entire quality assurance process.

A number of these states' requirements aim to ensure managed care plans develop and maintain provider networks that are sufficient to meet the needs of Medicaid beneficiaries. Some are criterion-based, such as patient-to-primary-care-physician ratios. For example, two states required that plans not exceed a maximum patient-to-primary-care-physician ratio of 2,500 to 1. Compliance with such a requirement, however, does not necessarily demonstrate that a network is sufficient to meet the needs of Medicaid beneficiaries. Patient-to-primary-care-physician ratios generally do not consider the number of networks a primary care physician participates in or a physician's capacity or willingness to see Medicaid patients. Of the states that we visited, only Arizona required physicians to report their work load in full-time-equivalent terms and identified primary care physicians who participate in more than one plan and could be counted more than once. The four states also require plans to provide a full range of specialty services, even if this means beneficiaries must be referred to providers outside the plan's network. However, because there are no established standards for specialists, these states have not specified the types and numbers of specialists to include in plan networks, making it difficult for these states to measure the adequacy of plan specialist networks before awarding a contract. Once plans have a contract, states can monitor the numbers and types of specialists participating in the network, but this does not necessarily indicate whether beneficiaries actually gain access to specialty care when they need it.

Given the difficulties associated with gauging the adequacy of a provider network, the four states that we visited have taken additional steps to assess the adequacy of the medical care that beneficiaries enrolled in managed care receive. For example, each state has looked at aggregated statistics on the use of specific services. Some have found that, compared with fee-for-service, Medicaid managed care recipients were more likely to receive certain preventive and diagnostic services, such as childhood immunizations and cancer screenings. Arizona, Tennessee, and Pennsylvania also have invested in developing encounter data—the individual-level data on all services provided to all patients. Encounter data can enable states to conduct their own analyses on a wider array of services than is possible using aggregated statistics. These analyses allow states to examine patterns of care across plans, such as differences in service delivery by selected types of services, beneficiary groups, and providers. To date, Arizona has made the most use of its encounter data, including using them as the state begins to develop quality indicators. Tennessee's early efforts primarily focused on developing and validating its encounter data; more recently, the state has begun to use these data to assess service utilization patterns. Pennsylvania's use of encounter data was even more limited. All four states also use data from plan-conducted clinical studies and state-conducted medical record audits to help assess patient care. Improved plan and state methodologies, however, could increase the usefulness of the data collected from these reviews.

The four states that we visited also have sought to assess the adequacy of patient care by tapping into information provided directly by Medicaid beneficiaries enrolled in managed care, such as patient satisfaction surveys and data gathered from grievance processes. While it is important to gauge patients' satisfaction with the care they receive, satisfaction data generally are not reliable measures of quality; most people lack the knowledge needed to adequately evaluate the appropriateness of the care they receive—or do not receive. In addition, newcomers to managed care may not fully understand how the system operates to effectively access services, advocate on their own behalf, or register dissatisfaction with their plan or provider. This is especially true for individuals with diverse language and cultural needs. Regardless, we found that if the states we visited improved certain methodologies for designing satisfaction surveys and stratified their survey and grievance data, they would have a better understanding of the needs and concerns of their Medicaid beneficiaries enrolled in managed care—especially those with special needs or chronic illnesses, who may experience problems in accessing services but whose numbers are too small to show up in analyses of broad-based data.

Background

Medicaid, a joint federal-state health financing program for the poor, provides health care for about 37 million low-income people.[3] In fiscal year 1996, Medicaid expenditures accounted for more than 20 percent of state budgets. To help control expenditures and expand access to health care, 36 states have mandated enrollment for some portion of their Medicaid population in managed care programs. As of June 1995, nearly 14 percent of Medicaid eligibles were enrolled in capitated programs.

Under a capitated managed care system, states pay contracted plans a monthly per-enrollee amount before services are delivered—a distinct departure from the traditional claims-based fee-for-service system in which providers are paid for each service as bills are submitted. In turn, the plans employ or subcontract with primary care physicians, who

---

[3] Medicaid was established in 1965 as title XIX of the Social Security Act (42 U.S.C. 1396 et seq.). Medicaid is administered at the state level, with federal oversight by HCFA within the Department of Health and Human Services (HHS).

coordinate the delivery of health services.[4] Some plans pay their subcontracted providers on a fee-for-service basis for care provided, while others pass certain financial risks on to providers by linking the providers' revenues or profits to the total number of services provided to plan enrollees. While capitated managed care has strong cost-containment incentives, it also provides incentives for plans and providers to limit services—not only must plans and providers absorb all costs that exceed the capitation rate, they profit if the capitation rate exceeds their costs.

Nationwide, most states initially implemented Medicaid capitated managed care programs by allowing beneficiaries to enroll on a voluntary basis in limited geographic areas. These programs were largely targeted to low-income families who received financial assistance under Aid to Families With Dependent Children (AFDC) and pregnant women and children who qualified for Medicaid. Increasingly, states are mandating beneficiary enrollment and expanding their programs to more geographic areas. In addition, they are beginning to include more populations with specialized needs, such as blind or disabled individuals who qualify for Medicaid under the Supplemental Security Income (SSI) program. As we reported in July 1996, 17 states had extended their Medicaid managed care programs to these more vulnerable populations.[5]

States must comply with certain federal statutory requirements for the development and oversight of their managed care programs. HCFA can waive some of these requirements—such as a beneficiary's freedom to choose any provider—to enable states to restrict beneficiaries to the providers participating in a managed care network. Waivers also allow states to expand the scope of their programs to populations not otherwise eligible for Medicaid. These waivers are of two types: program or demonstration.[6] Program waivers allow states to require beneficiaries to join a managed care plan, but beneficiaries are generally allowed to switch plans every 30 days. Demonstration waivers provide states with greater flexibility, and while they are more difficult to obtain than program waivers, they have been granted more frequently in recent years. States request demonstration waivers to establish mandatory programs that lock beneficiaries into one plan for periods of up to 12 months or to expand

---

[4] Primary care physicians may be general internal medicine practitioners, family and general practitioners, pediatricians, or obstetricians and gynecologists.

[5] See Medicaid Managed Care: Serving the Disabled Challenges State Programs (GAO/HEHS-96-136, July 31, 1996).

[6] Program waivers are authorized under section 1915 of the Social Security Act. Demonstration waivers are also known as section 1115 waivers, after the section of the Social Security Act that authorizes them.

eligibility to uninsured populations. Table 1 compares various characteristics of the two waiver types.

Table 1: Characteristics of Managed Care Programs Under Program and Demonstration Waivers

Program waivers	Demonstration waivers
General characteristics	
Allow for waiver of certain Medicaid requirements.	Allow for waiver of a broader range of Medicaid requirements.
Waivers renewed for 2- to 5-year periods.	Generally not renewed.[a]
Generally used to establish primary care case management programs and home-and community-based service programs.	More recently used to establish broad changes in Medicaid programs.
Characteristics pertaining to capitated managed care	
Plans must comply with 25% requirement for private enrollment.	Plans may enroll Medicaid patients exclusively.
Full range of mandatory services must be offered.	Benefit package may be modified.[b]
Beneficiaries may be mandated to enroll in plan and can be locked in for no longer than 1 month.[c]	Beneficiaries may be locked in for up to 12 months.

[a] The Congress has authorized renewal of some demonstration waivers.

[b] To date, only Oregon has been permitted to modify the benefit package for traditional Medicaid beneficiaries. Other states have been permitted to offer a modified package only to those newly eligible for Medicaid coverage under the demonstration.

[c] Lock-in is up to 6 months for capitated plans meeting certain federal requirements.

At the time of our review, Arizona and Tennessee had demonstration waivers for their mandatory statewide programs, which served both AFDC and SSI populations. Wisconsin had a program waiver for its mandatory program, which served only the AFDC populations in 5 of its 72 counties. In contrast, Pennsylvania had voluntary and mandatory managed care programs. The voluntary program—the larger program at the time of our review—served both AFDC and SSI populations in 13 of its 90 counties.[7] This program required no federal waiver.

To ensure that states comply with statutory and HCFA requirements, HCFA reviews state contracts with managed care plans. It also monitors state programs through independent evaluations and periodic reviews of state-submitted information on expenditures, medical services, and

---

[7] At the time of our review, 475,000 beneficiaries were enrolled in Pennsylvania's voluntary managed care program. With the February 1997 expansion of its mandatory program, 177,000 beneficiaries were participating in the voluntary program as of April 1, 1997; 66,000 are projected to be in the voluntary program by 1998.

enrollment data, which HCFA requires all states to report. The nature of HCFA's requirements and oversight role depends on the waiver type. For example, under a demonstration waiver, HCFA develops terms and conditions that vary by state, depending on the provisions being waived. (For a more detailed discussion of federal regulations and HCFA requirements for waiver programs, see app. II.)

Difficulties in Monitoring Managed Care Stem From Limited Standards of Care and Data on Service Utilization

Purchasers of managed care face a number of difficulties in ensuring enrollees receive the care that they need. In contrast to fee-for-service care—where the incentive is to oversupply services to increase revenues—capitated managed care, with its fixed payment system, contains incentives to provide fewer services to maximize short-term profits. Assessing how well the care delivered matches beneficiary needs is difficult because few aggregate or population-based utilization standards or benchmarks on delivery of care patterns have been established for managed care. Benchmarks derived from providers and patients in the fee-for-service sector may not be appropriate since service utilization patterns are expected to change under managed care.

Even where standards of care do exist for selected conditions or procedures, such as for prenatal care or childhood immunizations, monitoring the actual delivery of such services in capitated managed care is difficult because data on service utilization do not flow as readily as in a fee-for-service environment. In fee-for-service care, data on service delivery are captured in individual claims, which are submitted for payment as services are provided. In managed care, however, purchasers prospectively pay plans a monthly fee for services not yet provided. Unless plans capture service data in another form, it is difficult to identify the services actually provided. Without specific data collection requirements, providers may lack the incentive to accurately report individual-level data on all services provided since payment is not linked to documentation of the care provided.

To learn more about what transpires in the delivery of managed care services—and to help ensure that the health care services they contract for are appropriately provided—private and public purchasers also rely on other measurement tools and data sources. Among these are reviews of patient medical records and surveys of patients on the care they receive from plans. Reviews of medical records can help purchasers assess the care provided to individual patients. These assessments, however, are time-consuming and costly and are generally undertaken for small numbers of patients. Information from patients, while more accessible than medical records, can be problematic as well. Patients typically are not in a position to know what specific care or services they need for a given condition and often cannot assess the appropriateness of the care they receive—or do not receive. In addition, patients new to managed care may confuse differences in the way the system is meant to operate with deficiencies in the care provided. Problems associated with obtaining meaningful patient survey information may be even more pronounced for those in the surveyed population with unique language or cultural needs or who are unaccustomed to receiving routine health care in a structured system. Educating and informing prospective and newly enrolled beneficiaries about managed care and helping them learn how to use the system—as some states have done in their Medicaid managed care programs—can mitigate these problems.[8]

Most states are grappling with these and other issues associated with adapting and developing systems and processes for managed care—a relatively new health care environment. According to some experts, many states are struggling to maintain the staff needed to establish and oversee their programs, since frequent turnover of staff with managed care expertise is common. It is not surprising, then, that states are at various stages in their program development and monitoring efforts. The four states that we visited have taken a number of steps to overcome these various challenges and improve the odds that their money is well spent in their managed care programs. These states have established contract requirements that aim to ensure that participating managed care plans have the capacity to provide adequate care to enrolled Medicaid beneficiaries. Prominent among these requirements are standards for plans' provider networks. In monitoring participating plans, these states obtain information to assess actual services delivered from various sources, including plan-collected and -submitted data, state reviews of patient medical records, and beneficiaries' reports on their experiences.

Measures to Assess Beneficiaries' Access to Care Are Still Evolving

Before a contract is awarded, managed care plans must demonstrate that their provider networks are sufficient to meet the anticipated needs of enrolled Medicaid beneficiaries. In an attempt to measure provider network sufficiency, the states we visited—Arizona, Pennsylvania, Tennessee, and Wisconsin—have focused on quantitative or other measures related to primary care physicians and specialist care. But just

---

[8] See Medicaid: States' Efforts to Educate and Enroll Beneficiaries in Managed Care (GAO/HEHS-96-184, Sept. 17, 1996).

as there are few standards for health service utilization, there are few standards for what constitutes a sufficient provider network. Three of the four states have established a specific number of primary care physicians that a plan must have, and all require plans to provide a full range of specialty services. The states also have relied on criteria that measure beneficiaries' ability to reach their primary care physician within a reasonable time, in terms of maximum travel distances and waiting times. After contract award, the states use various monitoring techniques to determine the extent to which provider practices are in fact open to Medicaid beneficiaries. These measures, however, do not necessarily ensure that beneficiaries have access to the care that they need. Whether these measures provide meaningful information on beneficiary access is largely dependent on whether state monitoring efforts are independent and systematic and go beyond plan-reported, paper-based indications of compliance.

Compliance With Primary Care Physician Requirements Provides Incomplete Information About Network Adequacy

One criterion that states have established in an effort to ensure a sufficient provider network relates to the availability of primary care physicians, expressed as a ratio of enrolled beneficiaries per primary care physician.[9] At the time of our review, Arizona and Tennessee used a maximum patient-to-primary-care-physician ratio of 2,500 to 1, as required by the conditions of their demonstration waivers, and Pennsylvania required plans to meet a ratio of 1,600 to 1.[10] Wisconsin did not have specific contractual requirements for plans but looked for a ratio of approximately 1,200 to 1. To monitor plan compliance with these ratios, the states require plans to submit updated provider listings either annually, to coincide with contract renewal, or as frequently as monthly. The states also require plans to report all changes to the network as they occur and to note in their provider directories given to beneficiaries those providers who currently do not accept new patients.[11]

The states that we visited have found that plans in their managed care programs have complied with their patient-to-primary-care-physician ratios. But compliance with these ratios may not indicate actual physician capacity or Medicaid beneficiaries' access to care. We believe that the

---

[9] In 1994, there was one primary care physician for every 1,173 United States citizens (based on GAO analysis of the HHS Area Resource File).

[10] Beginning in October 1997, Arizona will require plans to have maximum patient-to-primary-care-physician ratios of 1,800 to 1 for adults and 1,200 to 1 for children under age 13.

[11] Typically, plan directories are updated annually; consequently, beneficiaries must directly contact the managed care plan for more current information on physician availability.

number of primary care physicians and their availability to treat patients may be overstated for two reasons. First, if the state reviews a plan's network capacity by looking at only that plan rather than looking at all plans collectively, providers who participate in more than one plan may be counted more than once. Second, if the state does not use full-time-equivalency data to determine network capacity, network physicians' other lines of business, such as treating Medicare or privately insured patients, are not taken into account. Of the states that we visited, only Arizona reviews provider participation across plans and assesses provider capacity in full-time-equivalency terms.

For patient-to-primary-care-physician ratios to be an effective measure of patient access to care, states must also ensure that plan physicians are actually available to treat Medicaid beneficiaries. Ratios simply indicate the number of physicians that have contracted with a plan; they do not indicate the number of patients physicians are willing to treat and the extent to which physicians actually provide services. Arizona and Pennsylvania independently assess the extent to which physician practices are open to Medicaid beneficiaries by periodically or randomly calling physician offices to determine whether they are accepting new Medicaid patients. When done on a systematic basis, these checks can better ensure that provider practices are open to Medicaid beneficiaries.

To improve oversight of its provider networks, Arizona increased plans' quarterly provider reporting requirements in September 1996. Previously, plans were required to report provider names and the number of beneficiaries seen by providers. Plans must now submit additional data on provider access, such as the maximum number of Medicaid beneficiaries that a provider will accept, the total number of beneficiaries currently assigned to a plan, the providers who are accepting new members, specialty services that are available, and foreign languages spoken by providers.

Specialist Mix Is Not Specified in Plan Contracts

Patients often require more specialized care than their primary care physician can provide—such as oncological, urological, or pediatric subspecialty care. Yet, assessing beneficiary access to such care is even more difficult than assessing access to primary care physicians. And as states move more beneficiaries with special needs or chronic conditions into managed care, ensuring beneficiary access to appropriate specialty services will become even more critical.

Assessing the availability of specialty providers within a network is problematic for at least two reasons. First, there are no criteria or standards—in fee-for-service or managed care—for the number and mix of specialists needed to serve a population or for when and how often beneficiaries should be referred to specialists. Second, some specialists—especially those that are used infrequently—often are not included in the network and can only be accessed outside the network. Since these specialists are not in the network, states cannot readily assess their availability to beneficiaries when needed.

The four states that we visited require that contracted plans provide a full range of specialty services, even if this requires referring beneficiaries to providers outside the plan's network. Without recognized standards, requirements for specialists are often vague and expressed in terms of an objective—such as, "provide access to necessary specialty care"—that cannot be measured before the contract award. While the four states do not specify in the contracts the types and numbers of specialists that plans must include in their networks, they do count the number and type of specialists available in any one plan. This is done by reviewing the listing of providers in a plan network during the contracting and contract renewal processes. Each of these states also reviews plan listings periodically and requires plans to report all changes in their specialty networks. For example, Tennessee officials told us that the state uses a zip-code-based computer program to check the location of specialists each quarter—or more frequently if inquiries or questions come up on a particular provider type. States then rely on the judgment of their experienced contract staff—which may include health care professionals—to determine whether the plans' specialist networks are adequate.

This type of review, however, does not inform states of the specialist services that Medicaid beneficiaries may use or request, especially if the services involve out-of-network referrals. In the absence of accepted standards for specialty care, states have relied on other information sources—such as data on service utilization and beneficiary satisfaction—to help them monitor the appropriateness of care provided.

Maximum Travel and Waiting Requirements Are Additional Criteria for Assessing Beneficiary Access to Care

As additional criteria for assessing the adequacy of provider networks, states commonly stipulate the maximum time and distance beneficiaries must travel to their primary care physician's office, the number of days they must wait for an appointment to see their physician, and the time they wait in the physician's office to be examined. These measures were developed on the premise that certain factors—such as lengthy travel times and distances, a physician's failure to schedule appointments in a timely manner, and excessive wait times in the physician's office—can discourage patients from seeking care.

In general, the states we visited established maximum travel requirements of 20 miles or 30 minutes for urban areas and 30 miles or 30 minutes for rural areas. For their specialist networks, the four states do not have or grant some exceptions to travel requirements, since significant portions of their Medicaid population can reside in rural areas where certain types of specialty care may not be available. These states also require providers to meet state-established standards for scheduling appointments and attending to beneficiaries in a timely manner.[12]

To determine whether plans are complying with the time and distance travel requirements, each state we visited reviews documentation on the location of provider sites prior to contracting with a plan and on a periodic schedule after contracting. Arizona and Tennessee, for example, use a computer-based zip-code program. This allows them to determine whether the locations of the primary care physicians and other providers in the network, such as dentists and hospitals, meet contractual time and distance requirements. In addition, each state requires plans to provide transportation for beneficiaries who require medical attention and who cannot get to their provider's location on their own, such as the elderly.

These four states use various approaches—involving plan-provided data or independent checks—to monitor provider compliance with wait-time requirements. For example, each state requires plans to include appointment standards in its subcontracts with providers and to review logs to ensure that providers comply. During their periodic compliance reviews, the states review the plans' procedures to ensure that providers have complied with the standards; the states also review selected sign-in and appointment books. For example, Tennessee found during one quarterly review of plan networks that some plans were not complying with the contractual travel requirements for their dental networks. According to state officials, the plans were notified of the deficiencies, and most took actions to resolve them. In at least one case, a plan did not take action and the state withheld 10 percent of the plan's capitation payment

---

[12] Generally, the four states' requirements to schedule appointments with primary care physicians are same-day appointments for emergency care, within 24 to 48 hours for urgent or sick care, and 2 to 3 weeks for routine preventive care. Requirements for in-office waiting times are generally 30 to 45 minutes. Some states also specify appointment standards for specialty referrals and dental services, as well as maternity, mental health, and substance abuse services.

until it was in compliance. States also have independently assessed provider compliance by periodically or randomly calling provider offices to schedule appointments. However, such periodic calls may not be systematic enough to provide the information required to identify problems. As one means of gaining additional insight into beneficiary experience with providers, Arizona and Tennessee have included questions in their beneficiary satisfaction surveys that are specifically related to wait times.

Systems for Assessing Adequacy of Medical Care Provided Can Be Further Improved

Recognizing the challenges associated with measuring the capacity of plan provider networks and their ability to ensure adequate care, states can use other accountability measures and processes to assess the actual care Medicaid beneficiaries receive. To identify average levels or recent changes in the use of services by beneficiaries enrolled in managed care, states can use plan reports of utilization statistics, which summarize selected services provided to specific populations. For more extensive analyses, states can use encounter data, which are individual-level data for each service provided to each enrollee. Encounter data allow states to identify the care received by any individual and the provision of any procedure. In addition, states can conduct, or require plans to conduct, other analyses—such as clinical studies and medical record audits—that review the full medical records to assess the appropriateness of the care received by a sample of beneficiaries.[13]

The four states that we visited have taken different approaches in implementing their data collection methods. For example, Pennsylvania and Wisconsin have relied primarily on collecting and using aggregated utilization statistics to measure the adequacy of care. Arizona and Tennessee also have required plans to collect and submit encounter data. However, both states have found that developing reliable and useful encounter data has required lengthy and continuing investment. As a result, these two states have primarily used their encounter data to identify services that may be over- or underutilized and health care areas on which to focus their studies and audits. Arizona has begun to use its encounter data to develop standards for measuring the quality of the care provided.[14] For all four states, we found that certain improvements in their

---

[13] For specific federal regulations and guidance related to these accountability measures and processes, see table II.1.

[14] Arizona further uses its encounter data to estimate the cost of serving beneficiaries in each county and to set capitation rates by county. See Arizona Medicaid: Competition Among Managed Care Plans Lowers Program Costs (GAO/HEHS-96-2, Oct. 4, 1995).

methodologies for conducting clinical studies and medical record audits could increase the usefulness of these reviews.

States Challenged to Develop Effective Utilization Statistics and Encounter Data for Monitoring Managed Care

Although utilization statistics and encounter data both capture patient use of services, utilization statistics are summary data that are generally relied on to show the frequency with which a service is accessed by a specific population. As such, there are several difficulties associated with using these summary statistics in assessing services provided under managed care. For example, utilization statistics are often compiled for only specific types of services, such as mammograms or childhood immunizations. Consequently, utilization statistics cannot be used to determine the full range of services that beneficiaries may receive. For example, in a prior study, we found that analyses of utilization statistics on early and periodic screening, diagnosis, and treatment (EPSDT) could not determine the actual number of EPSDT-eligible children who received required screenings or whether children with post-screen referrals actually received follow-up diagnosis and treatment.[15] Utilization statistics also have generally not been used to assess the performance of individual providers. To obtain utilization statistics for other sets of services or services supplied by individual providers, states would need to modify their reporting requirements—which could be problematic for plans if they have to alter their data systems or provider reporting requirements to meet new state requirements.

Unlike utilization statistics, which aggregate service use by a population, encounter data document all services that individual patients receive. While encounter data have certain limitations, these data provide states more flexibility to detect problems in beneficiary care by identifying patterns of service use by individual beneficiaries and services provided by individual providers. For example, these data can be used to assess the participation of any provider or group of providers and analyze patterns of care for specific diagnoses or procedures. With encounter data, states also can explore service delivery beyond what is captured by utilization statistics. These statistics allow plans and providers to "teach to the test," that is, focus on service delivery areas that they know will be measured, perhaps to the exclusion of other services. Since encounter data encompass all services for all beneficiary populations, all plan-provided services are subject to state review, and the services being reviewed can

---

[15] See Medicare Managed Care: More Competition and Oversight Would Improve California's Expansion Plan (GAO/HEHS-95-87, Apr. 28, 1995).

be changed periodically without adding to the administrative burden of plans.

Certain analyses of encounter data, however, are currently constrained by the limited number of benchmarks or standards against which states can measure the care provided for certain conditions. For example, while recognized standards exist for prenatal care and childhood immunizations, many diagnoses have multiple alternative treatments or therapies. Vocal chord stress, for instance, might be treated with medication, voice therapy, or surgery. Individual-level encounter data cannot show the appropriateness of many treatments provided to beneficiaries, nor can they provide information about beneficiaries who do not seek treatment. Regardless of these constraints, encounter data are valuable in that they support a wider array of analyses than do utilization statistics. Moreover, they provide the potential for supporting even more analyses as additional benchmarks are developed.

To ensure that the utilization statistics and encounter data are usable, data collection standards must be established and plans must be monitored for compliance with these standards. Validating the accuracy and completeness of encounter data requires additional measures—especially in a fully capitated system where provider payment is not directly linked to the documentation of each service provided. Although the data collection efforts in the four states that we visited varied considerably—due, in part, to the federal guidelines and requirements associated with their waiver type—overall, their use of encounter data to identify problems in beneficiary care has been minimal.

Wisconsin requires contracted plans to collect and submit on a quarterly basis utilization statistics on 59 types of health care services, including maternal and child health, mental health, and emergency room visits.[16] Using fee-for-service experience as the benchmark, the state analyzes—and publicly discloses in periodic reports—plan-submitted statistics on certain services, such as childhood immunizations; lead testing; mammograms; and dental, vision, and hearing examinations. For example, the state found that certain preventive services, such as Pap smears and childhood immunizations, increased in managed care, whereas emergency room visits decreased—a redistribution of service settings that is consistent with the goals of managed care. In addition, the state found

---

[16] For each indicator for which summary statistics are reported, plans also report a complete individual-level patient history file, which documents all services that the patient has received. This system allows Wisconsin to determine the actual number of beneficiaries who receive a service and to conduct more extensive analyses on areas of concern.

that beneficiary use of dental services was less in managed care than in fee-for-service care and took action to improve beneficiary access to these services. In relying on utilization statistics rather than on encounter data, however, Wisconsin cannot easily or independently assess the care that Medicaid beneficiaries receive beyond the 59 services. Such analyses would require encounter data for 100 percent of the services provided, which the state has opted not to collect in an effort to limit the administrative burden that collecting encounter data can place on the state and the plans.

Pennsylvania requires each plan participating in its voluntary managed care program to collect both utilization statistics and encounter data. But the state does not prescribe a method for collecting and validating the encounter data and does not require plans to routinely submit these data to the state for review and analysis.[17] In April 1996, the state required all plans to submit EPSDT data for a specific time period to respond to concerns regarding Medicaid beneficiaries' access to this service.

As part of their demonstration waiver requirements,[18] Tennessee and Arizona require plans to collect and submit encounter data on 100 percent of services, potentially giving these states the greatest flexibility in their analyses. Tennessee's efforts to date have focused on providing technical assistance to help plans configure their computer systems and data elements to ensure accuracy. HCFA is also providing the state with technical assistance in developing methodologies to analyze its encounter data. Despite these start-up issues, the state has begun to analyze its encounter data and to review provider practice patterns to identify potential over- or underutilization of care.

Of the states we visited, Arizona has the most comprehensive system for validating and analyzing plan-generated encounter data and has made the most use of these analyses to guide state actions. To ensure that its encounter data are accurate, complete, and timely, the state conducts two validation studies of plan-submitted encounter data each contract year. The first study takes a random sample of medical records and manually compares these records with the encounter data submitted by the plans. The second study compares the number of inpatient maternity

---

[17] Pennsylvania requires plans to submit encounter data for Medicaid beneficiaries enrolled in the state's mandatory managed care program. At the time of our review, 75,000 beneficiaries were enrolled in mandatory managed care. Nearly 500,000 are now enrolled as a result of the state's February 1997 expansion.

[18] HCFA requires all states with a demonstration waiver to collect encounter data for 100 percent of services.

hospitalizations with newborn reports from hospitals. The state also uses its encounter data to evaluate individual plan performance. Furthermore, beginning October 1997, Arizona will require plans to compile encounter data on specific measures, including mammography screening, cervical cancer screening, children's dental services, and well-child care.[19] In essence, Arizona will require plans to use their encounter data to compute certain utilization statistics. This should make the information available to the state sooner. Arizona also is creating a quality management system that uses outcome-based standards and, over the past several years, has been creating a baseline for these standards. The system will seek to produce data that could indicate whether preventive care—such as dental visits for children, mammograms, and Pap smears—prevent more serious health problems.

In the three states with mandatory managed care programs, plans may be sanctioned if they do not comply with utilization statistics or encounter data requirements. Tennessee assesses a 10-percent withhold on capitation payments for each month that a plan does not comply with data submission requirements. If the problem is not corrected within 6 months, the state keeps the withheld funds. Arizona imposes a financial penalty based on the number of data errors identified in its plans' encounter data. Wisconsin may impose financial penalties if plans do not meet accuracy and timeliness requirements. Over the last 2 years, the amount collected in penalties by Tennessee and Arizona has been minimal, and Wisconsin has not assessed any penalties.

More Targeted Clinical Studies and Medical Record Audits Are Needed to Assess Impact of Medicaid Managed Care

Recognizing the limitations of utilization statistics and encounter data, each of the four states that we visited uses reviews of samples of individual patient's medical records to determine whether appropriate and adequate care has been provided. Each state requires contracted plans to conduct at least one clinical study each year. A clinical study focuses on certain aspects of health care services, such as maternal health, to answer questions about the quality and appropriateness of care that has been provided. Each state also conducts its own medical record audits—as required by federal regulation—either internally or through a contracted external review organization, such as the State Peer Review Organization. Medical record audits also have the potential to assess the appropriateness

---

[19] The required measures are based on Medicaid Health Plan Employer Data Information Set (HEDIS). Medicaid HEDIS provides guidance that states may use to measure, improve, and report on health plan performance. Medicaid HEDIS was the collaborative effort of representatives from state Medicaid agencies, managed care plans, the National Committee on Quality Assurance (NCQA), professional health and welfare organizations, beneficiary advocacy groups, HCFA, the U.S. Public Health Service, and others.

of the care provided as well as determine whether patients' medical records properly document the health care and services that they received.

The states' current approaches to conducting these studies and audits could be improved to yield more useful findings. For example, we found that clinical studies often focus on the Medicaid population as a whole and less frequently target populations that may not fare as well under managed care, such as people with disabilities or chronic illnesses.[20] In addition, the states' sample sizes for its medical record audits appear to be insufficient to enable states to draw conclusions about the adequacy of the documentation of beneficiary care, particularly for certain populations or conditions too small to show up in pure random samples.

Managed Care Plans' Clinical Studies

Pennsylvania, Tennessee, and Wisconsin allow plans to select a topic to study from one or more health care areas that the state identifies.[21] In selecting study areas, the three states rely on the professional judgment and experience of staff in the state Medicaid agency and on independent expert opinion the states may seek. While studies of this nature can provide states with valuable information on plan performance and a baseline for evaluating subsequent plan performance, we found that the plan-conducted studies had several limitations. For example, only Wisconsin specified study areas that included conditions for which beneficiaries might require more care than the general Medicaid population, such as children with special care needs. Problems in the care for such beneficiaries may not be detected in studying samples of the overall Medicaid population because, relative to the larger population, their numbers are too small. In addition, allowing plans to select their clinical study topics gives them the latitude to select a topic where improvement may be needed, but it also allows them to select a topic that would yield positive results about plan performance. Finally, allowing plans to select topics to study does not enable states to compare results across plans for certain conditions or topics.

We also found that the states we visited conducted limited reviews of plan methodologies for clinical studies. Pennsylvania, for example, reviews plan methodologies during periodic quality assurance audits—after the plans' clinical studies have been completed. Wisconsin recently revised its process for reviewing plan methodologies. Previously, the state required

---

[20] See "Differences in 4-Year Health Outcomes for Elderly and Poor, Chronically Ill Patients Treated in HMO and Fee-for-Service Systems: Results From the Medical Outcomes Study," The Journal of the American Medical Association, Vol. 276, No. 13 (Oct. 2, 1996).

[21] Arizona requires plans to submit a topic for state approval.

plans to submit a one-paragraph description of their methodologies, on which the state would base its approval. For the contract year beginning October 1996, Wisconsin began to require plans to submit detailed descriptions of the study topic and the methodology for conducting the study. To validate the results of the plans' clinical studies, Pennsylvania and Tennessee review a sample of patient records during compliance reviews for their annual contracts. However, these states generally pull only a handful of records to verify the clinical study results.

States' Medical Record Audits

Medical record audits document problems with patient medical records, such as incomplete patient histories, lack of indication of follow-up care, and illegibility and unavailability of records. These audits also can help identify underlying causes of service delivery or access problems. If a plan's medical records are inadequate or indicate a service delivery problem, a state can require the plan to take corrective action. All four states that we visited use utilization statistics, encounter data, or both to focus their audits of Medicaid beneficiary medical records. For example, Wisconsin found through its analyses of utilization statistics that use of dental services was infrequent and, therefore, conducted a medical record audit to determine why Medicaid beneficiaries were not getting dental care.

While these states' periodic audits of beneficiary records have revealed weaknesses in the documentation of beneficiary care, we found that their audit methodologies often yielded results that were not statistically valid or may not have been sufficient to identify problems experienced by different groups of Medicaid beneficiaries. Specifically, the samples of records that the states used to conduct their audits generally were not stratified by specific conditions or populations—which could result in an underrepresentation of Medicaid beneficiaries with special needs—and the sample sizes may not have been adequate to identify areas that warrant further investigation. For example, Wisconsin uses a random sample of about 2 percent of cases for medical record audits. Arizona bases its sample sizes on the number of beneficiaries enrolled in a plan, with the sample sizes ranging from 30 to 100 patient records. Although the state agrees these sample sizes are not statistically valid, it believes that these audits, when combined with other periodic on-site reviews, are sufficient to identify best practices as well as problem areas to target for corrective action.

States Could Learn More From Improved Design and Analysis of Data on Beneficiary Experience With Managed Care

In assessing the performance of managed care plans, indicators of beneficiary satisfaction can complement other analyses of provider network capacity and the services provided. To gauge the extent to which beneficiaries are satisfied with Medicaid managed care and their managed care plan, the states that we visited review the results of beneficiary satisfaction surveys, grievance data, and the rates at which beneficiaries choose to switch plans or, if enrolled in a voluntary program, leave managed care altogether. While analyses of such data have helped these states identify problems that Medicaid beneficiaries have with managed care, such as difficulty in scheduling appointments or accessing specialists, certain improvements in the design of their surveys and data collection methods could enhance the usefulness of their analyses.

Improved Beneficiary Survey Designs Could Yield More Useful Data

Although the results of patient satisfaction surveys may not be the best indicator of quality care, periodic satisfaction surveys—administered statewide or at the plan level—can help measure the degree to which Medicaid beneficiaries are happy with the providers and services offered in their managed care plan. To ensure that survey findings are reliable and useful in identifying areas that need systemwide improvement, the survey design and process must be methodologically sound, however.[22] In addition, the survey must be designed to address several difficulties inherent in surveying the Medicaid population, such as effectively administering a survey instrument in multiple languages and overcoming historically low response rates.

Plan-Conducted Beneficiary Surveys

Pennsylvania, Tennessee, and Wisconsin require plans to conduct periodic surveys to assess beneficiary satisfaction with network providers and services. Pennsylvania and Tennessee review the plans' survey methodologies during their annual contract compliance reviews, but they do not routinely examine the survey methods before the surveys are conducted. Wisconsin requires plans to describe in detail the methodology they intend to use before the contract is awarded. Once the contract is awarded, the state reviews and approves each plan's survey methodology and instrument before it is administered. However, none of these states prescribes a methodology for conducting satisfaction surveys. Consequently, these states cannot compare survey results across plans.

---

[22] Medicaid HEDIS provides states with technical guidance on designing a satisfaction survey for Medicaid beneficiaries. This guidance includes how to identify topics for surveys and the trade-offs between phone and mail surveys, such as data collection costs, time required for data collection, response rates, sample sizes, and overall quality of data. In addition, HHS is developing beneficiary satisfaction surveys for both general and special needs populations, which should be of further help to the states once completed.

Statewide Surveys

Statewide surveys allow states to compare results across plans for various access and quality measures, such as use of specialty services, average waiting time for physician office visits, and beneficiary perception of the quality of care provided. As a condition of its demonstration waiver, Tennessee is required to conduct statewide satisfaction surveys annually. Arizona—on its own initiative—will soon complete a statewide beneficiary satisfaction survey. Pennsylvania and Wisconsin plan to conduct surveys as part of their planned program expansions.

Since implementing its managed care program in 1994, Tennessee has conducted two annual statewide surveys. HCFA required that the state's beneficiary satisfaction survey include questions on referrals to specialists, average waiting time for physician office visits, and reasons for disenrollment. Tennessee has used these surveys to identify trends in service use. For example, the state found that between 1993—the last year of fee-for-service care—and 1995, hospital use decreased 6 percent, and visits to doctors' offices increased 8 percent—a redistribution of service settings that is hoped for in managed care. In addition, its 1995 survey showed that 75 percent of enrollees were satisfied with the care they received through their managed care plan compared with a 61-percent satisfaction rate in 1994. Although this showed improvement in overall beneficiary satisfaction, the state also could use these survey results to further explore remaining causes of dissatisfaction for one fourth of the beneficiaries.

Arizona is issuing the results of its third statewide beneficiary survey in spring 1997.[23] The comprehensive survey included questions on the use of health services, time elapsed in getting an appointment with a physician and in waiting in the physician's office, problems with access to specialty care, and an overall rating of the plan and quality of care. The state conducted telephone interviews, which allowed interviewers to verify that they were speaking with the appropriate beneficiary and to ask appropriate follow-up questions. Of the current 450,000 beneficiaries enrolled in the program, over 14,000 were interviewed. The state intends to use the survey results to provide feedback to plans.

---

[23] Arizona's first survey, administered in 1989 by an advocacy group, was a comprehensive look at all health services used. The second, administered in 1995 by the Arizona State University Survey Research Laboratory, was a focused survey on prenatal and maternity care.

Targeted Analyses of Grievance Data Help Identify Areas That Need Improvement

To satisfy a federal requirement for operating a Medicaid managed care program, states must ensure that participating plans have an internal grievance process through which beneficiaries can report their dissatisfaction with plan providers, services, and benefits. Through these grievance processes, the states that we visited have been able to identify and address a number of beneficiary concerns. Some states also look at individual beneficiary grievances to identify specific and localized problems. Other opportunities for analyzing grievance data, however, exist. For example, monitoring the volume of grievances filed—particularly across plans—could reveal previously unidentified problems. Even a low number of grievances could indicate that beneficiaries do not understand the grievance process.

Arizona requires beneficiaries to submit grievances directly to the plan. Pennsylvania and Wisconsin have no such requirement but encourage this practice; they also allow beneficiaries to submit grievances directly to the state. Tennessee requires beneficiaries to submit grievances directly to the state. After receiving a grievance, the plans must provide beneficiaries with resolution and action in a reasonable time frame, ranging from 30 to 90 days. If a beneficiary is not satisfied with a plan's decision, the beneficiary can appeal to the state. Most grievances are resolved at the plan level, however, according to officials in the states we visited. At a minimum, the plans that directly receive grievances are required to periodically report to the state the number and type of grievances they received—such as denial of requests for out-of-plan services or difficulty in locating a provider or in scheduling an appointment—and the status of these cases. To probe beyond such aggregated information, which may mask specific or localized problems, Arizona and Wisconsin informed us that they review each grievance that plans receive.

In addition to the grievance process, each state has developed other means for beneficiaries to voice their concerns. For example, Tennessee has a toll-free information hotline to respond to beneficiary questions and concerns. Tennessee also sponsors hotlines run by advocacy groups to answer questions posed by beneficiaries with special needs, such as persons with acquired immune deficiency syndrome (AIDS) or human immunodeficiency virus (HIV), hemophiliacs, and persons with disabilities, as well as the general Medicaid population. In addition to state-run hotlines, Wisconsin requires each plan to have a beneficiary advocate who serves as a liaison between the state, the plan, and the beneficiary. The plan advocate identifies major areas of concern, such as lack of access to mental health care, and works with the plan and the state to correct the problem. This can obviate the need for beneficiaries to register grievances.

States' Analyses of Disenrollment Data Could Help Identify Problem Areas

Beneficiaries who disenroll from a managed care plan may do so because of dissatisfaction with the care they receive through the plan. Therefore, collecting and analyzing data on disenrollments can provide important insights into plan performance. In a voluntary program, such as the one we visited in Pennsylvania, beneficiaries can switch plans or return to fee-for-service care. In mandatory programs—such as those in Arizona, Tennessee, and Wisconsin—beneficiaries can switch plans during open seasons, which occur every 6 or 12 months.[24] The states we visited, however, generally do not conduct routine disenrollment studies.

According to officials in these states, they would conduct a disenrollment study if a significant number of disenrollments were detected.[25] They believe that disenrollments—especially in low numbers—could signify a number of occurrences other than beneficiary dissatisfaction or problems with the plan. For example, in 1992, Arizona conducted a disenrollment study and found that most of the beneficiaries who changed plans during open enrollment—which was less than 5 percent of all beneficiaries in managed care—did so for reasons other than plan dissatisfaction. Specifically, the state found that some beneficiaries disenrolled because they wanted to continue to see a provider who was no longer in their plan's network. Others switched to have all family members in one plan, and still others wanted to enroll in a plan where provider location was more convenient. Unless it sees a substantial change in enrollment rates during an annual open season, Arizona has no plans to conduct another study.

More analyses of these disenrollment data—even if the rate at which beneficiaries leave or switch plans is low—could reveal significant problems. Disenrollments concentrated in an area or among people having similar needs, such as people with AIDS, may indicate a potential problem in a plan. Also, any plan having higher disenrollment rates than other plans may merit scrutiny to determine the reason.

---

[24] Under a demonstration waiver, states can obtain federal authorization to require beneficiaries to remain enrolled in a specific health plan for 12 months. Under certain circumstances, such as relocation, beneficiaries can change plans at other times.

[25] In 1995, disenrollment rates in Arizona and Tennessee—the two demonstration waiver states where enrollment only changes annually—were 4 and 6 percent, respectively.

Observations

In view of the billions of dollars that are being paid prospectively to managed care plans and the questions about the degree to which managed care is meeting the health care needs of Medicaid beneficiaries, there is a new demand for public accountability. The continuing trend toward expansion of mandatory, capitated Medicaid managed care programs requires that states have the ability to adequately oversee their contracts with health plans and ensure that states get what they are paying for. However, developing systems to hold plans accountable for ensuring that Medicaid beneficiaries receive the care that they need has been a challenge for states—especially since there are few benchmarks and standards against which states can measure beneficiary access to network providers and the appropriateness of the care provided.

The four states that we visited have made progress toward developing accountability measures to ensure that beneficiaries have access to quality care. As they expand or refine their Medicaid managed care programs, these states continue to scale the steep learning curve to becoming an effective purchaser of managed care. Yet, to instill greater public confidence that managed care can effectively and efficiently meet the health care needs of Medicaid beneficiaries, more effort is needed. For example, to varying extents, these states could improve their methodologies for collecting and analyzing data—especially encounter data—on beneficiary care. They could better target their clinical studies, medical record audits, beneficiary satisfaction surveys, and reviews of grievance data on specific services and beneficiary groups—particularly those with special needs or conditions whose numbers may be too small to show up in broad-scale surveys or studies. The need for these improvements takes on even greater importance for those states planning to expand their managed care programs to other geographic areas or populations, such as people with disabilities or other special needs.

Agency Comments and Our Evaluation

We provided a draft of this report to the Administrator, HCFA. We also provided a draft to Medicaid officials in each of the four states we visited and to independent experts and researchers from the Center for Health Care Strategies, Medical College of Virginia, and National Academy for State Health Policy. Each provided technical or clarifying comments, which we incorporated as appropriate.

In addition to technical comments, each state informed us of recent or planned initiatives for ensuring plan and provider accountability in their programs. For example, in February 1997, Pennsylvania implemented

HealthChoices—a mandatory managed care program projected to serve more than a half million Medicaid beneficiaries in the state by 1997. With this new program, Pennsylvania plans to improve those accountability measures used under its voluntary program or adopt new accountability measures, such as disenrollment studies. HCFA, Arizona, and Wisconsin also noted that the draft did not discuss all accountability or quality assurance measures that were in use at the time of our review and were concerned that the account of state efforts was incomplete. In the final report, we state that the focus of our work was on 10 key measures or processes that states commonly use to assess plan accountability—not on each state's entire quality assurance process.

Arizona and Wisconsin also commented that the draft report did not reflect in all respects their experience with managed care. For example, they disagreed with our premise that since managed care plans receive prospective capitated payments, there is a financial incentive to limit or not provide needed services. HCFA echoed this comment. The two states pointed out, for example, that the use of certain preventive services increased when they moved to managed care. In response to their comments, we revised the report to include examples of their experience in the changing patterns of care under managed care. Nevertheless, in a prepaid capitated system, the incentive remains to provide fewer services in order to maximize short-term profits, as the HCFA Administrator recently testified before the Senate Committee on Finance. Concern about plans and providers having a short-term focus is exacerbated by the fact that significant numbers of beneficiaries frequently gain and lose Medicaid eligibility within a short period of time.

Arizona also made a number of comparisons between managed care and fee-for-service and suggested that our report include such comparisons. The purpose of our report was not to weigh the merits of one system against those of another. Rather, we set out to identify potential problems Medicaid beneficiaries may have in accessing services through managed care and state efforts to address these access issues.

Several reviewers, including HCFA, agreed with our conclusion that certain measures of physician capacity do not adequately ensure beneficiary access to care. It was suggested that we report on other important criteria states use to assess the adequacy of provider networks—specifically, beneficiary travel and waiting times. The final report reflects additional information on this issue.

Finally, the experts we consulted generally agreed with the accuracy and comprehensiveness of our presentation of the issues. They also emphasized that the transformation of existing state systems and processes to an effective managed care program—especially one with meaningful oversight mechanisms—requires great change accompanied by continuous refinements and adaptations. Each state—with varying levels of experience with managed care, resources, and in-house expertise—understandably approaches this evolutionary process with varying strategies and time frames. Even as states confront their many challenges in implementing managed care, strong and consistent accountability systems remain integral to their success in meeting the needs of Medicaid beneficiaries. This perspective is more fully reflected in the final report.

As arranged with your office, unless you announce its contents earlier, we plan no further distribution of this report until 30 days after the date of this letter. At that time, we will send copies of this report to the Secretary of Health and Human Services, the Administrator of HCFA, state officials in the four states we visited, appropriate congressional committees, and other interested parties. We will also make copies available to others upon request.

Please contact me on (202) 512-7114 or Kathryn G. Allen on (202) 512-7059 if you or your staff have any questions. Major contributors to this report are listed in appendix III.

Sincerely yours,

William J Scanlon

William J. Scanlon
Director, Health Financing and
Systems Issues

Contents

Tables

Abbreviations

AFDC	Aid to Families With Dependent Children
AIDS	acquired immune deficiency syndrome
EPSDT	early and periodic screening, diagnosis, and treatment
HCFA	Health Care Financing Administration
HEDIS	Health Plan Employer Data Information Set
HHS	Department of Health and Human Services
HIV	human immunodeficiency virus
HMO	health maintenance organization
NCQA	National Committee on Quality Assurance
SSI	Supplemental Security Income

Appendix I

Scope and Methodology

To ensure quality in their Medicaid managed care programs, states use a number of quality assurance and oversight mechanisms. For example, some states require accreditation of plans by independent entities, such as the National Committee on Quality Assurance. Most states build into their contracts with managed care plans a variety of accountability measures and processes. Once states have contracted with plans, they monitor the plans to ensure that they comply with these requirements.

Based on our review of federal requirements and guidelines and state contracts and supporting documents, we identified a number of accountability measures and processes that states commonly include in their contracts with managed care plans. States can rely on various controls to assess compliance with some of these measures—including plan licensing, physician credentialing, and fiscal solvency requirements. Some accountability measures are more difficult to develop controls for and, therefore, are more difficult to monitor.

To assess state efforts to hold managed care plans accountable for meeting Medicaid program goals and providing beneficiaries enrolled in capitated managed care plans the care they need, we narrowed the focus of our study to three areas: ensuring an adequate provider network, tracking the medical care provided to beneficiaries, and assessing beneficiary satisfaction. From among numerous quality assurance measures and processes, we identified 10 that states commonly use to monitor plan compliance in these accountability areas. Health Care Financing Administration (HCFA) officials and experts we contacted agreed that these measures and processes are essential to ensuring that plans meet the terms of their contracts. (See table I.1.)

Table I.1: Selected Accountability Measures and Processes

Accountability area	Measure or process
Adequacy of provider network	—Patient-to-primary-care-physician ratio —Access to specialists —Travel distances and waiting times
Adequacy of medical care	—Utilization statistics —Encounter data —Clinical studies —Medical record audits
Beneficiary satisfaction	—Satisfaction surveys —Grievance procedures —Disenrollment data

To examine how these accountability measures and processes were implemented, we visited four states—Arizona, Pennsylvania, Tennessee, and Wisconsin—and reviewed their systems for ensuring access to quality care in their managed care programs. To select these states, we first identified a universe of 14 states that, as of June 1994, had more than 100,000 beneficiaries enrolled in capitated Medicaid managed care programs. We chose that date because we believed that, even for states just entering the managed care market, they would have had at least 2 years at the time we began our review to develop and implement their accountability systems. We then judgmentally selected four states that would provide a mix of experiences for a variety of factors. These factors included type of program (Medicaid demonstration waiver, program waiver, or voluntary nonwaiver), years of managed care experience, size of program, and geographic diversity. (See table I.2 for a brief description of each state's Medicaid managed care program.)

Table I.2: Description of the Four States' Medicaid Managed Care Programs That GAO Reviewed

State	Program name and description
Arizona	Arizona Health Care Cost Containment System is a mandatory statewide demonstration program, operational since 1982, with Aid to Families With Dependent Children (AFDC) and Supplemental Security Income (SSI) enrollment of over 450,000 in 14 participating health plans. Arizona did not have a Medicaid program before the waiver.
Pennsylvania	The state's voluntary nonwaiver program has been operational since 1972, with enrollment of about 435,000 AFDC and SSI beneficiaries in 18 counties in 11 health maintenance organizations (HMO) as of June 1996. (The scope of our work focused on the state's voluntary program.) The state also had a mandatory program, Health Pass, in certain areas of Philadelphia from 1986 to January 31, 1997. On February 1, 1997, a new program waiver, HealthChoices, began in 5 Philadelphia-area counties; the voluntary program will continue in 13 counties. Within the next 2 years, the state plans to apply for a statewide demonstration waiver.
Tennessee	TennCare is a mandatory, statewide demonstration waiver program, operational since 1994, with enrollment of 849,000 AFDC and SSI Medicaid beneficiaries and over 334,000 uninsured persons in 12 participating HMOs at the time of our review.[a]
Wisconsin	The state's mandatory program waiver for its AFDC population has been operational since 1984 in 5 counties, with enrollment of 138,000 in 11 participating HMOs. A modified waiver was approved October 1, 1996, to expand mandatory enrollment to 68 of the state's 72 counties.

[a] As of January 1997, Tennessee began to contract solely with HMOs. Before this, Tennessee also contracted with other health plans, such as preferred provider organizations.

For each state, we reviewed the contractual and other requirements the states have established with plans for these selected accountability indicators. We also interviewed officials from the state Medicaid, health, and insurance agencies to discuss specific contract requirements with managed care plans, state oversight activities and state actions available or taken as a result of monitoring, and state plans for changes in and expansions to their managed care programs.

To identify federal requirements and guidance available to states to oversee their Medicaid managed care programs, we interviewed officials from HCFA's central office and Chicago and Philadelphia regional offices, the Department of Health and Human Services' (HHS) Office of Inspector General, and state-level advocacy groups. We also interviewed experts with The George Washington University Center for Health Policy Research, the National Association of Managed Care Regulators, the National Committee on Quality Assurance, and the National Association of Insurance Commissioners. Finally, we consulted with the following experts and researchers in the course of our work: Jane Horvath, National Academy for State Health Policy, Washington, D.C.; Robert Hurley, Medical College of Virginia, Richmond, Virginia; and Stephen Somers and Karen Brodsky, Center for Health Strategies, Princeton, New Jersey.

We performed our work between October 1995 and March 1997 in accordance with generally accepted government auditing standards.

Federal and State Oversight Roles of Medicaid Managed Care

By virtue of the mandated federal-state Medicaid partnership, states must meet certain federal requirements when developing their managed care programs. States may implement managed care programs under one of three options. The first option is a nonwaiver program that allows states to contract with managed care plans to deliver health care services to Medicaid beneficiaries who voluntarily participate. Certain conditions must be met, such as allowing beneficiaries the freedom to stay in a traditional fee-for-service system or enroll with a managed care plan from which they can disenroll at any time. Plans also must adhere to a "75-25 rule," which prohibits participating managed care plans from enrolling 75 percent or more Medicaid and Medicare beneficiaries. The managed care program in Pennsylvania that we reviewed is a program of this type.

The other two options for managed care—program and demonstration waivers—allow HCFA to waive certain provisions of the Medicaid statute, including beneficiaries' freedom to choose from among participating providers. Under a program waiver, enrollment can be mandatory, but states are still required to ensure that plan enrollment of Medicaid and Medicare beneficiaries does not reach 75 percent and, in most cases, plans cannot lock in enrollment for more than 1 month. Wisconsin operates its mandatory managed care program under a program waiver. Under a demonstration waiver, states may be given permission to contract with plans that do not comply with the 75-25 rule and to exclusively enroll Medicaid beneficiaries. They also have been permitted to lock in beneficiary enrollment for up to 12 months. The managed care programs in Arizona and Tennessee are statewide mandatory programs operated under demonstration waivers. In addition, some states, such as Tennessee, have used demonstration waivers to expand eligibility to include non-Medicaid-eligible people who were formerly uninsured.

Certain federal regulations, requirements, and guidance influence the development of state managed care programs and state monitoring of managed care plan performance. The extent of these requirements often depends on waiver type and can vary by state. In general, HCFA monitors the planning for and implementation of demonstration waivers more than for program waivers. The initial terms and conditions of approval for demonstration waivers are more detailed than for program waivers and are more specific in the content and timing of reporting requirements. For example, HCFA's terms and conditions for a demonstration waiver have required that states specify in their contracts with plans a specific patient-to-primary-care-physician ratio that plans must meet. HCFA also requires that most states establish travel-related requirements for plan networks, such as maximum times and distances beneficiaries must travel to reach their primary care physician. In contrast, under a program waiver, HCFA suggests that states establish a patient-to-primary-care-physician ratio or that providers be located near beneficiaries. Under demonstration waivers, HCFA also requires states to provide an overall quality assurance monitoring plan and, as part of that plan, requires states to specify a minimum data set of encounter data. This minimum data set must receive prior HCFA approval. Program waivers, in contrast, have guidelines on quality assurance programs but not as many specific requirements. For example, HCFA does not require states to develop encounter data under program waivers.

Table II.1 summarizes federal requirements and guidance by selected accountability measures and processes.

Table II.1: Federal Regulations, Requirements, and Guidance for Selected Accountability Measures and Processes Within States' Medicaid Managed Care Programs

Accountability measure or process	Federal regulation	Additional HCFA requirements and guidance[a]
Patient-to-primary-care-physician ratio	Plans must ensure that beneficiaries in managed care have the same access to providers and services as beneficiaries in fee-for-service plans. (42 C.F.R. 434.20(c)(2))	For demonstration waivers, states must meet maximum 2,500 to 1 ratio. For program waivers, HCFA suggests ratios be evaluated.
Availability of specialists	Services are to be the same as those provided under fee-for-service plans. (42 C.F.R. 434.20(c)(2))	HCFA suggests that states have a system for authorizing and coordinating specialty services.
Utilization statistics and encounter data	Requires plans to maintain appropriate record systems for services provided to enrollees. (42 C.F.R. 436.6(a)(7))	HCFA requires all states with demonstration waivers to collect 100% encounter data and requires all states to quarterly report aggregated statistics on selected services.
Clinical studies	Plans must have an internal quality assurance system. (42 C.F.R. 434.34)	HCFA suggests states conduct quality-of-care studies.
Medical record audits	States must annually conduct an audit of medical records. (42 C.F.R. 434.53)	HCFA requires states to comply with federal regulation for medical record audits.
Beneficiary satisfaction surveys	Plans must have an internal quality assurance system. (42 C.F.R. 434.34)	For demonstration waivers, a state may be required to conduct a survey as HCFA prescribes. For program waivers, HCFA suggests plans conduct periodic surveys.
Grievance procedures	Plans must have an internal grievance procedure approved by the state that provides for prompt resolution. (42 C.F.R. 434.32)	HCFA requires states to report grievance data quarterly.
Disenrollment studies	States must monitor enrollment and termination practices. (42 C.F.R. 434.63)	HCFA suggests states analyze enrollment statistics.

[a] For demonstration waivers, additional requirements and guidance are in the terms and conditions that HCFA develops when it approves a state's waiver request. These terms and conditions can vary by state. For risk-based managed care plans, such as program waivers, HCFA's guidance is included in Monitoring Risk-Based Managed Care Plans: A Guide for State Medicaid Agencies, report prepared under contract for the Medicaid Bureau/HCFA by the Medicaid Management Institute of the American Public Welfare Association (Washington, D.C.: HHS, July 1993).

Appendix III

Major Contributors to This Report

Kathryn G. Allen, Acting Associate Director, (202) 512-7059
Karyn L. Papineau, Evaluator-in-Charge, (202) 512-7155
Karin A. Lennon, Senior Evaluator
Karen M. Sloan, Communications Analyst
Betty J. Kirksey, Evaluator
Daniel S. Meyer, Senior Evaluator

PRINTED ON RECYCLED PAPER

United States General Accounting Office

GAO Report to Congressional Requesters

July 1996

MEDICAID

Waiver Program for Developmentally Disabled Is Promising But Poses Some Risks

G A O 75 years 1921 - 1996

GAO/HEHS-96-120

GAO

United States
General Accounting Office
Washington, D.C. 20548

Health, Education, and
Human Services Division

B-266320

July 22, 1996

The Honorable William S. Cohen
Chairman
The Honorable David H. Pryor
Ranking Minority Member
Special Committee on Aging
United States Senate

The Honorable Bill Frist
Chairman
Subcommittee on Disability Policy
Committee on Labor and Human Resources
United States Senate

Adults with developmental disabilities are highly dependent on public programs for meeting their long-term care needs. Most persons with developmental disabilities have mental retardation, but others have severe, chronic disability resulting from cerebral palsy, epilepsy, or other life-long conditions, except mental illness, that began before they were 22 years old. The population with developmental disabilities receives more than $13 billion annually in public funding for long-term care, second only to the elderly. More than 300,000 adults with developmental disabilities receive government long-term services financed primarily through Medicaid and to a lesser extent through state and local programs. Long-term care services can include supervision and assistance with everyday activities such as help in dressing, going to the bathroom, managing money, and keeping out of danger. Persons with developmental disabilities have traditionally received their long-term care in institutional settings.

Recently, states have begun to significantly expand the use of the Medicaid 1915(c) home and community-based waiver, enacted by the Congress in 1981, to provide alternatives to institutional care for persons with developmental disabilities.[1] The waiver program has two advantages. First, it gives states a tool to control costs by allowing them to limit the number of recipients served. In contrast, states must serve all eligible individuals in the regular Medicaid program. Second, it permits states to meet the needs of many persons with developmental disabilities by offering them a broader range of services in less restrictive settings such as group or

---

[1] States also use the waiver for other populations. See Medicaid Long-Term Care: Successful State Efforts to Expand Home Services While Limiting Costs (GAO/HEHS-94-167, Aug. 11, 1994).

family home, rather than in a Medicaid intermediate care facility for mental retardation (ICF/MR), the setting where most of the institutional care for this population is provided.

At your request, we examined states' experiences in utilizing the flexibility offered by the Medicaid waiver program to provide care for adults with developmental disabilities in alternative settings. To understand changes in services, cost, and quality assurance, we reviewed national data and conducted three case studies on issues and choices states faced in using the waiver program. Specifically, we examined (1) expanded state use of the waiver program, (2) the growth in long-term care costs for individuals with developmental disabilities, (3) how costs are controlled, and (4) strengths and limitations in states' approaches to assuring quality in community settings.

To conduct our work, we reviewed the literature, interviewed Health Care Financing Administration (HCFA) officials responsible for waiver programs and national experts, and analyzed national data on Medicaid expenditures and recipients. We also performed case studies in three states: Florida, Michigan, and Rhode Island. We chose these states because they have large waiver programs, provide a range in state size and geographic representation, and have different strategies for using the waiver program. In visits to these states, we interviewed program officials, providers, recipients, families, and advocates. We also reviewed data on costs and program participation for these states. We conducted our review between May 1995 and May 1996 in accordance with generally accepted government auditing standards. For a complete description of our scope and methodology, see appendix I.

Results in Brief

State use of the Medicaid 1915(c) home and community-based waiver has changed the face of long-term care nationally for persons with developmental disabilities by providing more persons with the kind of services that most recipients and families prefer. It has significantly expanded the number of persons served overall and resulted in more people being served by the waiver program in group home and home settings than in the more restrictive and often large ICFS/MR. Florida, Michigan, Rhode Island, and other states have used the waiver program to pursue various objectives, such as closing many large and some small ICFS/MR, expanding services to persons previously in state-financed programs, and including persons not previously served. Waiver program services have been provided primarily in group homes. However, some states have begun to shift the focus of their waiver programs to serve more people at home—their own home, their family's home, or an adult foster care home—and to provide a broader range of services tailored to individuals' needs and preferences.

From 1990 to 1995, Medicaid costs for long-term care services for persons with developmental disabilities nationwide rose at an average annual rate of 9 percent. Although most of the increase reflected increased costs for waiver program services, increased costs for ICF/MR program services also were a factor. Waiver program costs grew primarily because more people were served as per capita costs for the program increased slightly less than inflation. ICF/MR program costs increased even though the number of ICF/MR residents declined 7 percent. The program's cost increases resulted solely from per capita cost growth for the ICF/MR program, which was somewhat higher than inflation.

If not for a cap on the number of waiver program recipients in each state and state management practices, cost growth would likely have been higher. HCFA requires each state to set limits on the number of persons to be served in the waiver program subject to federal approval. Therefore, HCFA allows states to deny services to otherwise eligible individuals once the cap is reached. In contrast, the regular Medicaid program requires that states serve all those who meet eligibility requirements. In addition, states use their own management practices to control costs. In the three states we visited, these management practices include fixed agency budgets for waiver program services and linking of the management of the care plan and use of non-Medicaid services to individual budgets for each person served.

A 1994 change in federal rules could result in higher caps and costs. In this change, HCFA eased the process by which waiver program caps were established, giving states more discretion in determining the number of waiver program recipients. In doing so, HCFA recognized the risk of cost increases if states increased the number of people served, but it expected that state budget pressures would likely inhibit the size of the increase. If states elect to use this discretion, as two states we visited said they planned to do, a risk exists that the number of waiver program recipients and costs could increase more rapidly.

Some states are changing their quality assurance approaches to improve quality as services offered by the waiver program continue to evolve, but more development is needed to reduce risks. States continue to use traditional mechanisms such as provider certification to assure recipient safety. At the same time, states are introducing promising innovations to customize quality assurance for an individual's circumstances. For example, states may use a combination of methods to monitor quality, including arranging for a roommate to live with a disabled individual; home visits from community volunteers to check on an individual's status; and visits from program staff at locations where the individual is likely to be, such as his or her home or local park or library. At the heart of this effort is the recognition that reducing the level of program restrictions and the amount of supervision in these individuals' lives and increasing their choices of where they live, whom they live with, and what they do during the day are desirable goals but can pose risks because of the cognitive and physical impairments of the population served. State officials recognize that increasing recipient choice and making providers compete can play an important role in improving the quality of services provided. But they and HCFA officials acknowledge that more remains to be done to fully develop the quality oversight mechanisms being used. Until this occurs, some recipients may not have better service quality and may face some health and safety risks.

Background

Medicaid funds most publicly supported long-term care services for persons with developmental disabilities. In 1995, Medicaid provided more than $13.2 billion to support over 275,000 individuals with these services. To be eligible for Medicaid, individuals must generally meet federal and state income and asset thresholds. To be considered developmentally disabled, individuals must also have a mental or physical impairment, with onset before they are 22 years old, that is likely to continue indefinitely and they must be unable to carry out some everyday activities, such as making basic decisions, communicating, taking transportation, keeping track of money, keeping out of danger, eating, and going to the bathroom, without substantial assistance from others.

Until recently, states provided the bulk of services for this population through the Medicaid ICF/MR program. The ICF/MR program funds large institutions and smaller settings of 4 to 15 beds, and both sizes of settings are subject to the same regulatory standards. ICF/MR program services are available and provided as needed on a 24-hour basis. These services include medical and nursing services, physical and occupational therapy, psychological services, recreational and social services, and speech and audiology services. ICF/MR program services also include room and board. Providers of ICF/MR program services must adhere to an extensive set of regulations and are subject to annual on-site inspections as mandated by Medicaid.

In 1981, the Congress enacted the 1915(c) waiver allowing states to apply to HCFA for a waiver of certain Medicaid rules to offer home and community-based services. By 1995, 49 states had 1915(c) home and community-based waiver programs for persons with developmental disabilities.[2] Waiver program services vary by state, but include primarily nonmedical services such as chore services, respite care, and habilitation services, which are all intended to help people live more independently and learn to take care of themselves. (See apps. II and III for a list of waiver program services and definitions in the three states we visited). Unlike ICF/MR program services, waiver program services do not include room and board and are often provided on less than a 24-hour basis.

HCFA carries out its waiver program oversight responsibilities through review of applications and renewals and monitoring of implementation through on-site compliance reviews. In approving waivers,[3] HCFA reviews applications to ensure that (1) services are offered to individuals who, "but for the provision of such services . . . would require the level of care provided" in an institutional setting such as an ICF/MR;[4] (2) total Medicaid per capita costs for waiver program recipients are not greater than total Medicaid per capita costs for persons receiving institutional care; and (3) states properly assure quality.

The waiver program enables states to control utilization and costs in ways not permitted under the regular Medicaid program. The waiver program has a cap for the number of persons served at HCFA-approved levels. It also allows states, with HCFA permission, to target services to distinct geographic areas or populations, such as persons with developmental disabilities or the elderly; offer a broader range of services; and serve persons with incomes somewhat higher than normal eligibility thresholds. In contrast, the regular Medicaid program generally requires that each state provide eligible beneficiaries with all federally mandated services and any optional services it chooses to offer.

States, however, provide some community-based services to developmentally disabled individuals through the regular Medicaid

---

[2] Arizona provides similar services through a Medicaid 1115 demonstration waiver.

[3] Initial waiver program approvals are for a 3-year period and renewals are for a 5-year period.

[4] Section 1915(c)(1) of the Social Security Act.

program. These services include federally mandated services, such as home health care, and other services that states may elect to provide, which are called optional services. Some of the more important optional services for the population with developmental disabilities are rehabilitative services,[5] case management, and personal care. Because the regular Medicaid program operates as an entitlement—that is, all eligible individuals in a state are entitled to receive all services offered by the state—states have less control over utilization and the cost of services than in waiver programs.

States Use Waivers to Expand and Change Programs for Developmentally Disabled

Through the use of waivers, states have changed long-term care nationally for persons with developmental disabilities in two ways. First, states have significantly expanded the number of individuals being served. Second, states have shifted the program balance from serving most people through the ICF/MR program to serving most through the waiver program. Generally the shift to the waiver program has been part of an evolution of services away from large and more restrictive settings to providing services in small and less restrictive settings, which are preferred by recipients and their families. Some state waiver programs are continuing to evolve from their earlier approach of providing services primarily in group home settings to one of serving people at home.

States Serve More People and Shift Balance by Serving More in Waiver Than in ICF/MR Program

From 1990 to 1995 the number of persons served by the waiver and ICF/MR programs combined rose at an average annual rate of 8 percent (see table 1). The number served by the waiver program more than tripled to over 142,000 persons during this period and accounted for the entire increase in the number of persons served by both programs. States dramatically increased the number of people who received waiver program services using a variety of strategies, including substituting waiver program for ICF/MR program services, services provided under state-only programs, and services to persons who were not being served before.

---

[5] Some states use the Medicaid optional service of rehabilitation to provide services to persons with developmental disabilities. However, HCFA considers the services provided under this option for the developmentally disabled population to be habilitation rather than rehabilitation because these services are intended to help individuals learn to perform tasks rather than restore their ability to perform tasks they have lost the capacity to perform. HCFA no longer allows states to select the rehabilitation plan option to offer habilitation services. However, states that had received approval to do so before June 30, 1989, can continue providing such services.

Table 1: Growth of Developmental Disabilities Population Served by Medicaid Long-Term Care

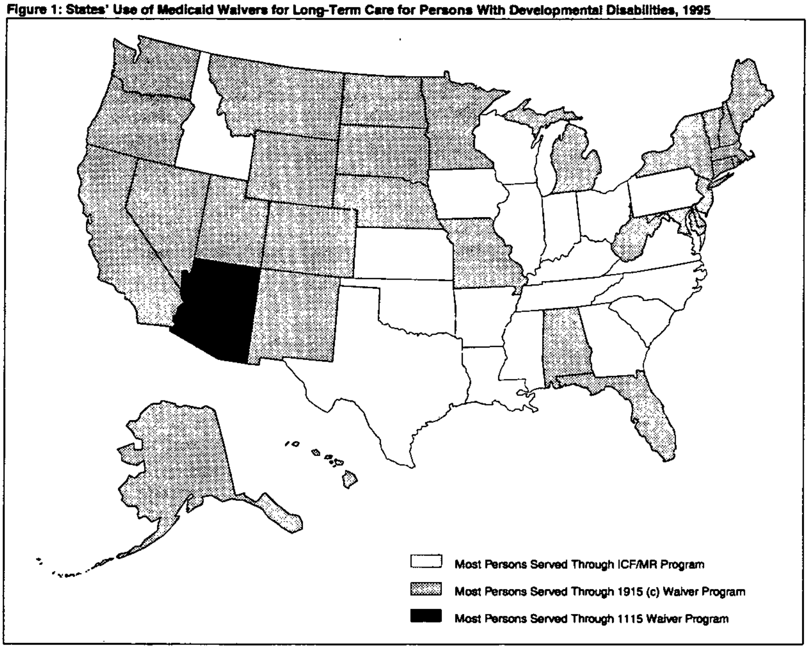
Recipients	1982	1986	1990	1994	1995
Total	**140,593**	**156,505**	**184,126**	**257,420**	**276,452**
Served by waiver program[a]	1,381	17,180	39,838	115,302	142,068
Served by ICF/MR program	139,212	139,325	144,288	142,118	134,384

[a] Does not include those served by Arizona's 1115 waiver program who live in alternative settings.

Source. Research and Training Center on Community Living, Institute on Community Integration/UAP, College of Education and Human Development, University of Minnesota, Minneapolis.

More people are now served through the waiver program than the ICF/MR program. Although the percentage of persons served through the waiver program varies by state, 30 states provide services to more people through the waiver program than the ICF/MR program (see fig. 1).

Figure 1: States' Use of Medicaid Waivers for Long-Term Care for Persons With Developmental Disabilities, 1995



Source: Calculated from data obtained from the Research and Training Center on Community Living, Institute on Community Integration/UAP, College of Education and Human Development, University of Minnesota, Minneapolis.

With the support of recipients and their families, state officials have made changes to serve more people through the waiver program. All three groups have come to believe that the alternatives possible through the waiver can better serve persons with developmental disabilities. They believe that in many cases individuals can have a higher quality of life through greater community participation, including relationships with neighbors, activities in social organizations, attendance at public events, and shopping for food and other items. This can result in expanded social networks, enhanced family involvement, more living space and privacy, and improvements in communication, self-care, and other skills of daily living.

States believed that they could use the waiver program to expand services while simultaneously reducing or limiting access to ICF/MR program care as a means to control growth in expenditures. As a result, many states have closed large institutions or held steady ICF/MR capacity even as the population in need has grown. Some states have also reduced smaller ICF/MR settings by converting them to waiver programs. The number of people in ICF/MR settings has dropped 7 percent from 1990 to 1995. These actions have been part of an overall strategy to change the way services are provided and financed.

Flexibility of the Waiver Program Has Allowed States to Pursue Distinct Strategies

States have used the flexibility of the waiver program to pursue distinct strategies and achieve different program results as shown in the three states we visited (see table 2). These states used the waiver program to substitute for ICFS/MR that were being closed, expand the number of persons being served, or both.

Table 2: Changes in Number of Waiver and ICF/MR Program Recipients, 1990 and 1994

	1990		1994	
State	Waiver program recipients	ICF/MR program recipients	Waiver program recipients	ICF/MR program recipients
Florida	2,488	3,243	6,547	3,395
Michigan	1,647	3,337	3,130	3,205
Rhode Island	738	903	1,262	458

Note: Some double counting occurs for recipient numbers because the same individual may receive services through the waiver and ICF/MR programs in the same year.

Source: State agencies.

Rhode Island targeted waiver program services as a substitute for ICF/MR program care with little change in the number of persons served. The state began the 1990s with short waiting lists for services and a goal of closing all large institutions of 16 or more beds. Providing waiver program services to many of its former residents, the state closed the Ladd Center, its last large institution, in 1994 to become one of only two states along with the District of Columbia to close all its large institutions.[6] Rhode Island also substantially reduced the number of recipients of services in smaller ICFS/MR by converting the ICFS/MR to the waiver program. As a result, a substantial number of persons who had been supported through the state's ICF/MR program are now supported by its waiver program. The number of developmentally disabled persons served through the waiver and ICF/MR programs in Rhode Island, however, did not expand significantly.

In contrast, Florida's strategy for the waiver program was to expand services to a much broader population rather than using the waiver program to close ICF/MR settings. Florida began the 1990s with substantial waiting lists for services and fewer ICF/MR beds than most of the country relative to the size of the population with developmental disabilities. Florida chose to greatly expand the number of persons with developmental disabilities served to include people who had not been served or who needed more services. The overwhelming source of growth has been from the large increase in waiver program recipients, although Florida has also experienced modest growth in the number of ICF/MR recipients. The state's increase in waiver program recipients includes persons who were receiving services from state-only programs and persons who were not previously served.

Michigan used the waiver program in the 1990s to continue pursuing its goals of closing large institutions, offering placements for persons leaving small ICFS/MR, and expanding services to those with unmet needs. Michigan, like Florida, began the 1990s with many persons who needed but had not received services. Michigan, however, had more ICF/MR capacity than Florida. Most of Michigan's ICF/MR capacity was in smaller settings, many of which had been developed to help the state close some of its large institutions. As a result, Michigan has closed all but about 400 beds in large institutions and significantly increased the number of persons served. State officials told us that by 1995, Michigan was serving more individuals in the waiver program than in its ICF/MR program.

---

[6] Vermont is the other state to close all its ICFs/MR of 16 or more beds. New Hampshire is the only other state to close all its large state institutions, but it still has one large private institution in operation.

States Are Changing Their Waiver Programs to Serve More Individuals at Home

In the continuing evolution of services for persons with developmental disabilities, some states, such as Florida, Michigan, and Rhode Island, are changing the focus of waiver program services from group home care to more tailored services to meet individuals' unique needs and preferences at home. These states and most others began their waiver programs by providing services primarily in group homes. Recently, state officials have come to believe that for many persons, services are best provided on a more individualized basis in a recipient's home—his or her family's home or own home or an adult foster care home—rather than in group home settings. The three states we visited became convinced that this was possible even for persons with severe disabilities, in part, because of their success in using this approach in the recently concluded Community Supported Living Arrangements (CSLA) program.[7]

Slightly more than one-half of all waiver program recipients nationally are estimated to have been living in settings other than group homes in 1995.[8] In each of the three states we visited, many 1915(c) waiver recipients now live in their family's home or their own home. In Florida, more than one-half of all waiver recipients live in settings other than group homes, including nearly 50 percent who live in their family's homes. The majority of Michigan's waiver program recipients live in small settings other than licensed group homes. Just under one-half of Rhode Island's recipients live in settings other than group homes. Each state expects the percentage of waiver program recipients living in nongroup home settings to increase.

Officials in the states we visited and other experts told us that serving individuals with developmental disabilities who live in their own or their family's home and receive less than 24-hour support often requires changes in the service delivery model. For example, these settings may need environmental changes and supports to make them suitable for persons with developmental disabilities. Such changes could include the installation of ramps for persons with physical disabilities or emergency communication technology and other equipment for persons with communication or cognitive impairments or a history of seizures who may need quick assistance. Paid assistance may also be needed to provide a

---

[7] Starting in 1990, the Congress funded the CSLA program for a 5-year period. The eight states selected to participate in the program used CSLA to expand or test a fundamentally different approach to supporting people with disabilities in the community, often referred to as the supports model. The program ended in 1995. CSLA expenditures were $38 million in 1995.

[8] Robert Prouty, and and K. Charlie Lakin, eds., Residential Services for Persons With Developmental Disabilities: Status and Trends Through 1995 (Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration/UAP, College of Education and Human Development, 1996), p. 102.

variety of other services, such as supervision of or assistance in toileting, dressing, bathing, carrying out routine chores, managing money, or accessing public transportation and other community services. Assistance for such services is often provided on an individual basis rather than for several persons in a group home. Respite care may also be provided for family caregivers.

Although the three states we visited have made major commitments to convert their waiver programs to individualized supports at home, these changes will require significant change on the part of everyone involved and could take years to fully implement. For example, some public agencies own or have long-term contracts for the use of group homes or have encouraged the development of private group homes. In addition, state officials told us that public agencies and other service providers may find it difficult to adapt to designing services for each individual living at home rather than offering services in the more familiar group home program setting. In addition, some family members and advocates have expressed concern that the level of funding available for and the range of services offered under the waiver program may not be sufficient for individuals who require constant supervision and care.

Medicaid Costs Rose During Planned Expansion in Persons Served

Nationwide, Medicaid costs for long-term care services for persons with developmental disability rose at an average annual rate of 9 percent between 1990 and 1995 as states implemented their planned increases in the number of persons served. Costs rose from $8.5 billion in 1990 to $13.2 billion in 1995. (See table 3.) Most of the increase reflected increased costs for waiver program services, but increased ICF/MR program costs also were a factor. Waiver program costs grew primarily because more people were served as per capita waiver costs increased slightly less than inflation. ICF/MR program cost increases resulted solely from growth in per capita ICF/MR program costs, which rose somewhat faster than inflation, as the number of residents declined. In 1995, per capita waiver program costs ($24,970) remained significantly lower than per capita ICF/MR spending ($71,992).[9]

---

[9] Although Medicaid costs are much lower for waiver program recipients than ICF/MR program recipients, government savings are less for waiver program recipients than this comparison might suggest. For example, waiver program recipients receive other government funding not available to ICF/MR program recipients. Furthermore, although waiver program recipients can receive federal Supplemental Security Income (SSI) payments for general income, ICF/MR program recipients can only receive the SSI personal needs allowance. In 1995, the general income maximum was $458 a month or $5,496 annually, while the personal needs allowance was $30 a month. The amount of SSI payments can be greater if states choose to supplement the federal payment. Waiver program recipients may also benefit from the Food Stamp program, some federal housing programs, and state and local government programs.

Table 3: Growth in Medicaid Long-Term Care Costs for Persons With Developmental Disabilities, 1990, 1994, and 1995

Dollars in billions

Program	1990	1994	1995
Total	**$8.478**	**$12.085**	**$13.222**
Waiver program[a]	0.846	2.862	3.547
ICF/MR program	7.632	9.222	9.675

Note: Numbers may not add due to rounding.

[a] Does not include costs for Arizona's 1115 waiver program for services in alternative settings.

Source: Research and Training Center on Community Living, Institute on Community Integration/UAP, College of Education and Human Development, University of Minnesota, Minneapolis.

State Costs and Cost Increases Vary

In the three states we visited, average per capita costs and average increases in per capita costs varied according to each state's waiver program strategy and other factors (see table 4). Florida per capita waiver costs, for example, were among the lowest in the nation, in part, as a result of the state's strategy to expand services to more persons. According to state officials, limited resources were stretched to cover as many people as possible by providing each individual with the level of services required to prevent institutionalization rather than providing all the services from which an individual might benefit.

Table 4: Per Capita Costs and Cost Increases Vary

	Per capita costs, 1994		Average annual percentage increase in per capita costs, 1990-94	
	Waiver program	ICF/MR program	Waiver program	ICF/MR program
United States	$24,824	$64,892	4	5
Florida	9,955	62,815	9	8
Michigan	27,537	66,361	5	1
Rhode Island	49,884	117,118	27	11

Source: Calculated from national data obtained from the Research and Training Center on Community Living, Institute on Community Integration/UAP, College of Education and Human Development, University of Minnesota, Minneapolis, and state data provided by state officials. Because 1995 data were not available from the states, we use 1994 national data for comparison purposes. See appendix I for details on national and state data comparison.

By contrast, from 1990 to 1994 Rhode Island's per capita costs under the waiver and ICF/MR programs were much higher than the national average.[10] The large increase in per capita waiver program costs resulted because unlike Florida and Michigan, Rhode Island substituted waiver program services for persons receiving high-cost ICF/MR care and closed its last large institution. As a result, Rhode Island was serving a substantial number of persons through the waiver program who had previously received expensive ICF/MR care. At the same time, ICF/MR per capita costs were also higher, in part, because as the number of people in ICF/MR settings declined, the fixed costs were spread over a smaller population. In addition, the population that remained in ICF/MR settings was substantially disabled and required intensive services.

Enrollment Caps and Management Practices Helped Limit Cost Growth

Cost growth has been limited by two factors. First is a cap on the number of program recipients. Second, states have employed a variety of management practices to control per capita spending.

Fundamental to waiver program cost control has been the federal Medicaid rule which, in effect, capped the number of recipients who could have been served each year. HCFA approves each state's cap, and states are allowed to deny admission for services to otherwise qualified individuals when the cap is reached. By contrast, under the regular Medicaid program, all eligible recipients must be served and no limits exist on the number of recipients. As a result, waiver caps have given states a greater ability to control access and thereby cost growth than would have been possible if they had expanded services through the regular Medicaid program.

States have also used several management practices to help contain costs. In the three states we visited, these management practices include fixed agency budgets for waiver services and linking management of care plan and use of non-Medicaid services to individual budgets for each person served.

Fixed Agency Budgets

States have developed fixed agency budgets within limits established under waiver rules. In Florida, Michigan, and Rhode Island, appropriations for waiver program and other services are in the budgets of developmental disability agencies. In Florida, budgets are allocated among 15 state district offices. In Michigan, budgets for serving persons with

---

[10] Per capita costs for both programs are substantially higher in New England than in most other parts of the country.

developmental disabilities are allocated among 52 local government community mental health boards and three state-operated agencies, each responsible for serving a local area. State or local agencies are responsible for approving individual service plans, authorizing budgets for the costs of these services, and monitoring program expenditures on an ongoing basis to ensure that total expenditures are within appropriated budgetary amounts as the three states transition to a person-centered planning basis in their waiver programs.

Management of Care Plan Linked to Individual Budgets

The three states we visited require that case managers or service providers in consultation with case managers develop a plan of care linked to an individual budget for each person being served in the person-centered planning approach. This care plan and its costs must be approved by the state developmental disability agency, state district office, or community mental health board, depending upon the state. Upon agency approval, the case manager oversees the implementation of the care plan and monitors it on an ongoing basis. Significant variation from the plan requires agency approval and changes in service and budget authorizations. This process provides more stability for the budget process and allows state agencies to monitor their overall spending on an ongoing basis and plan for contingencies to remain within budget levels.

Use of Non-Medicaid Services Linked to Individual Budgets

State developmental disability agencies in the three states we visited also require that case managers build into the care planning process and individual budget determination the use of non-Medicaid services, both paid and unpaid. State officials told us that this is a part of better integration of persons with developmental disabilities into the community and making it possible to extend available waiver dollars to serve as many people as possible. When paid services are needed, states try to take advantage of services funded for broader populations, such as recreation or socialization in senior citizen centers or the use of public transportation. States also attempt to use unpaid services when possible by increasing assistance from families, friends, and volunteers. State officials told us that use of these paid and unpaid services reduces the need for Medicaid-financed supervision and care.

Change in Federal Rule Could Result in Higher Caps and Costs

A change in federal rules could result in high waiver caps on enrollment and therefore higher costs. Until August 24, 1994, HCFA limited the number of waiver recipients in a state under the so-called cold bed rule. This rule required that each state document for HCFA approval that it either had an unoccupied Medicaid-certified institutional bed—or a bed that would be built or converted—for each individual waiver recipient the state requested to serve in its application. However, in 1994, HCFA eased waiver restrictions by eliminating the cold bed rule so that states were no longer required to demonstrate to HCFA that they had "cold beds."

HCFA took this action because it believed that the cold bed rule placed an unreasonable burden on states by requiring them to project estimates of additional institutional capacity. HCFA now accepts a state's assurance that absent the waiver the people served in the waiver program would receive appropriate Medicaid-funded institutional services. As HCFA recognized when it eliminated the cold bed rule, this change could result in higher waiver costs if states elect to increase the number of waiver recipients more rapidly than before. HCFA, however, recognized that the state budget constraints could play a restrictive role in waiver growth.

State officials told us that elimination of the cold bed rule allows them to expand waiver services more rapidly than in the past, both to persons not currently receiving services and to others receiving services from state-only programs. State officials told us that converting state program recipients to the waiver was particularly advantageous given the federal Medicaid match.[11] Officials in Florida and Michigan told us that they are planning to expand the number of people served in the waiver program more rapidly than they could have under the cold bed rule. This could increase costs more rapidly than in the past. Officials in Florida and Michigan said that they will phase in increases in the number of waiver recipients to stay within state budget constraints and to allow for a more orderly expansion of services to the larger numbers of new recipients.

---

[11] The federal government matches state expenditures for Medicaid according to a prescribed formula, providing on average 57 cents of every Medicaid dollar spent.

More Development of Promising Quality Assurance Approaches Needed to Reduce Potential Risks

To increase quality for recipients and families, states are introducing promising quality assurance innovations while simultaneously building in more flexibility in traditional quality assurance mechanisms. These changes are intended to provide recipients and families with a greater choice of services within appropriate budget and safety limits. However, until states more comprehensively develop and test these approaches, some recipients may face health and safety risks and others may not have access to the range of choices state programs seek to provide.

States Continue to Use Traditional Mechanisms to Assure Adequate Quality

One of the most important mechanisms that states use to assure adequate quality is service standards. Each state, as required by HCFA guidelines, adopts or develops standards for each waiver service. Waiver standards are specified in state and local laws, regulations, or operating guidelines and are enforced by specific agencies. As a result, waiver standards reflect specific state processes and choices in how states assure quality, and are not uniform across the nation as are ICF/MR standards. (For example, see app. IV for a summary of how Florida meets HCFA requirements for specifying waiver standards.) Waiver standards may include professional licensing standards, minimum training requirements for staff, and criminal background checks for providers. The standards may also include requirements for certification of group home or other facilities and compliance with local building codes and fire and safety requirements.

States review providers and services on an ongoing basis and have abuse and neglect reporting procedures in place. Florida, Michigan, and Rhode Island, for example, conduct routine and unannounced reviews of providers. As a result of these reviews, providers can be required to provide plans of correction for identified problems and implement improvements. In some cases, providers have lost their certification to participate in the program. These states also have formal grievance procedures and a grievance unit, such as a state agency or human rights committee, to investigate complaints on a statewide, regional, or agency basis. Through these processes, the states have also identified problems in quality and taken steps to ensure corrective action.

In addition to state quality assurance efforts, HCFA regional staff conduct a compliance review of each state's waiver program before its renewal. HCFA uses a compliance review document for this process. HCFA reviews involve random selections of recipients for interviews and visits to their homes. The reviews also involve interviews with and visits to service providers and advocates. If HCFA determines that quality is not satisfactory, it can require that a state take corrective action before a waiver can be renewed.

States Are Introducing Innovations to Promote Better Quality for Recipients

States are taking steps to develop or enhance existing mechanisms to promote better quality in waiver program services. Many of these mechanisms were used in the recently concluded CSLA program to provide individualized services to people at home and are now being incorporated into the home and community-based waiver program even for persons with substantial disabilities. Advocates, family members, and recipients have been generally positive about this shift to support individuals in more integrated community settings.

Person-centered planning is a key element of providing better quality in waiver services, according to officials in the three states we visited and national experts. The planning process and the resulting plans are individualized to incorporate substantial recipient and family input on how the individual will live and what assistance the individual will need. The case manager, called support coordinator in some states, has primary responsibility in person-centered planning, which includes working with the recipient to develop the plan, arranging for needed services, monitoring service delivery and quality, and revising the plan as necessary. A budget for the individual is established to provide the services identified as appropriate and cost-effective. Recipients and case managers choose providers on the basis of their satisfaction with services. State officials told us that this approach not only gives recipients more say in how they are served but that the resulting competition motivates providers to increase service quality.

Linking persons living in the community with volunteers who can provide assistance and serve as advocates is seen as another important mechanism for promoting quality. For example, some states, including the three we visited, have a circle of friends or similar process for individual recipients. A circle of friends is a group of volunteers, which can include family, friends, community members, and others, who meet regularly to help persons with disabilities reach their goals. These volunteers help plan how to obtain needed supports; help persons participate in community, work, or leisure activities they choose; and try to help find solutions to problems. By integrating recipients in the community, recipients have more choice and can get better quality services, according to national experts and state officials we interviewed. This community integration increases the number of persons who can observe and identify problems in service quality and notify appropriate officials when there are deficiencies.

Because program quality depends on the active participation of recipients, families, and service providers, states are also providing substantial training to these groups to encourage and strengthen their participation. Training can include informing recipients and families of available service providers, procedures for providing feedback about services, and steps to take if quality is not improved. Training for service providers may focus on reinforcing the fact that the recipient and family have the right to make choices about services and that staff must be responsive to those choices unless they are inappropriate for safety concerns or for other compelling reasons, such as available financial resources.

States are also modifying how they monitor quality. Traditionally, they emphasized compliance with certain criteria, such as maintaining a minimum level of staff resources and implementing standard care processes. Some states are focusing their quality monitoring more on outcome measures for each individual while still assessing providers' compliance with program standards. For example, states, including the three we visited, are trying to determine whether the recipients are living where and with whom they chose, whether they are safe in this environment, and whether they are satisfied with their environment and the services they receive.

States are also attempting to make their oversight less intrusive for the recipients. For example, some states use trained volunteers to interview recipients at their homes on a periodic basis to check the quality of services received. In other instances, although case managers are required to meet recipients on a regular basis, meetings can be arranged at the recipient's convenience, including in the evening or on weekends or at a place the recipient likes to meet at, such as at his or her home or local park or library. Case managers talk with the recipients and their families about the quality of the services they receive and take any actions necessary to correct deficiencies.

Some Recipients May Face Avoidable Risks Until States More Fully Develop and Implement Evolving Approaches to Quality

While officials in the three states we visited and other experts agree that many persons prefer services provided at home to services provided in institutions or other group settings, they also note that providing services at home presents unique problems in ensuring quality. Because the new focus is on providing individual choice, the types of services that are offered and the means for providing these services can vary greatly. To promote quality and ensure that minimum standards are met requires a broad range of approaches.

Although states continue to develop quality assurance mechanisms, state officials acknowledge that these are not yet comprehensive enough to assure recipient satisfaction and safety. In the three states we visited, state officials and provider agencies told us that they are still developing guidance and oversight in a number of key areas. Michigan, for example, is revising its case management standards and statewide quality assurance approaches. Rhode Island is developing a more systematic monitoring approach statewide, and Florida is continuing to implement and evaluate its independent service coordinator approach.

One of the greatest difficulties in developing quality mechanisms for services in alternative settings is balancing individual choice and risks.[12] Where greater choice is encouraged and risks are higher, more frequent monitoring and contingency planning need to be built into the process. Yet some professional staff and agency providers in the states we visited believe that they do not have sufficient guidance on where to draw the line between their assessment of what is appropriate for the disabled person and the individual's choice. For example, some persons with mental retardation cannot speak clearly enough to be understood by people who do not know them; cannot manage household chores, such as cooking in a safe manner; or have no family member to perform overall supervision to keep them from danger. Yet these people express a desire to live independently, without 24-hour staff supervision.

Florida, Michigan, and Rhode Island each attempt to customize supports to reduce risks for individuals who live in these situations. They may arrange for roommates, encourage frequent visits and telephone contact by neighbors and friends, enroll individuals in supervised day activities, install in-home electronic access to emergency help, and provide paid meal preparation and chore services. As this new process evolves, states and providers seek to develop a better understanding of how to manage risks and reduce them where possible. This should lead to improved guidance for balancing risks and choices for each recipient's unique circumstances.

---

[12] HCFA has also recognized the need to balance these issues. See The Role of Medicare and Medicaid in Long-Term Care: Opportunities, Challenges, and New Directions (Baltimore: U.S. Department of Health and Human Services, HCFA, Sept., 1995), p. 44.

Determining what recipients' choices are can be difficult for a number of reasons. First, many of these individuals have had little experience in making decisions and may also have difficulty in communicating. In addition, some recipients have complained that they are not being provided the range of choices to which they should have access and that quality monitoring is too frequent or intrusive despite the changes states have introduced. However, concern has been expressed that quality assurance is not rigorous enough to reduce all health or safety risks and that the range of choices is too great for some individuals.[13]

State officials and other experts we interviewed have emphasized the need for vigilance to protect recipients and ensure their rights. They have been especially concerned with assuring quality for recipients who are unable to communicate well and for those who do not have family members to assist them. The states we visited are taking special precautions to try to assure quality in these cases—such as recruiting volunteers to assist and asking recipient groups to suggest how to assure quality for this vulnerable population. However, state officials and HCFA agree that more development of quality assurance approaches is needed.

Agency Comments

Officials from the Office of Long-Term Care Services in HCFA's Medicaid Bureau and from Florida, Michigan, and Rhode Island reviewed a draft of this report. They generally agreed with its contents and provided technical comments that we incorporated as appropriate.

---

[13] See Robert G. Erb, "Perspectives: Where, Oh Where, Has Common Sense Gone? (Or If the Shoe Don't Fit, Why Wear It?), Mental Retardation: A Journal of Policy, Practices, and Perspectives, Vol. 33, No. 3 (1995), pp. 197-99.

We are sending copies of this report to the Secretary of Health and Human Services; the Administrator, Health Care Financing Administration; and other interested parties. Copies of this report will also be made available to others upon request.

If you or your staff have any questions, please call me at (202) 512-7119; Bruce D. Layton, Assistant Director, at (202) 512-6837; or James C. Musselwhite, Senior Social Science Analyst, at (202) 512-7259. Other major contributors to this report include Carla Brown, Eric Anderson, and Martha Grove Hipskind.

William J Scanlon

William J. Scanlon
Director, Health Systems Issues

Contents

Figures

Abbreviations

ASPE	Assistant Secretary for Planning and Evaluation
CMHB	Community Mental Health Board
CSLA	Community Supported Living Arrangements
DS	Developmental Services
F.S.	Florida statutes
HCFA	Health Care Financing Administration
HIV/AIDS	human immunodeficiency virus/acquired immunodeficiency syndrome
HRS	Department of Health and Rehabilitative Services
ICF	intermediate care facility
ICF/MR	intermediate care facility for mental retardation
NASDDDS	National Association of State Directors of Developmental Disabilities Services, Inc.
NF	nursing facility
PERS	Personal Emergency Response System
SNF	skilled nursing facility
SSI	Supplemental Security Income
UAP	University Affiliated Program

Appendix I

Scope and Methodology

We focused our work on Medicaid 1915(c) waivers for adults with developmental disabilities. We also examined related aspects of institutional care provided through ICF/MR, state plan optional services, and the CSLA program, all under Medicaid.

To address our study objectives we (1) conducted a literature review, (2) interviewed national experts on mental retardation and other developmental disabilities, (3) collected national data on expenditures and the number of individuals served, and (4) collected and analyzed data from three states. National experts interviewed included officials at HCFA; the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services; the Administration on Developmental Disabilities; the President's Committee on Mental Retardation; the National Association of Developmental Disabilities Councils; the Administration on Aging; the National Association of State Directors of Developmental Disabilities Services, Inc. (NASDDDS); and the ARC, formerly known as the Association for Retarded Citizens. We also interviewed researchers at University Affiliated Programs (UAP)[14] on developmental disabilities at the Universities of Illinois and Minnesota and Wayne State University.

We conducted our case studies in Florida, Michigan, and Rhode Island. We chose these states for several reasons. The three states provide a range of state size and geographic representation. Each state has a substantial developmental disability waiver program that serves more people than its ICF/MR program. Experts told us that these states would provide examples of different state strategies for utilizing the Medicaid waiver. This included their policies regarding large and small institutions as well as the design and implementation of their waiver programs. The three states also have important differences in the administrative structure of their developmental disability programs. Rhode Island administers its waiver program statewide through the Division of Developmental Disabilities in the Department of Mental Health, Retardation and Hospitals. Florida places statewide administration and oversight responsibility for its waiver program in Developmental Services, the Department of Health and Rehabilitative Services, but operational responsibility rests with its 15 district offices of Developmental Services. Michigan places statewide administration and oversight responsibility for its waiver programs in the state Department of Mental Health, but operating responsibilities rest with 52 Community Mental Health Boards (CMHB), which are local government

---

[14] University affiliated programs are funded by the Administration on Developmental Disabilities as part of the Developmental Disabilities Act to provide information and analysis on developmental disability programs.

entities covering one or more counties and three state-operated agencies each responsible for serving a local area. Florida district offices and Michigan CMHBs have discretion in the design and implementation of waiver program and other services within the broad outlines of state policy.

We visited each state to conduct interviews with state and local officials, researchers, service providers, advocates, families, and recipients. These interviews included state Medicaid officials and developmental services officials and officials in agencies on aging and developmental disability councils. In Florida, we also visited state district offices in Pensacola and Tallahassee to conduct interviews with district government and nongovernment representatives. In Michigan, we visited the Detroit-Wayne and Midland/Gladwin CMHBs to conduct interviews with government and nongovernment representatives. We followed up with state agencies to collect additional information.

The national waiver and ICF/MR program expenditure and recipient data used in this report are from the UAP on developmental disabilities at the Research and Training Center on Community Living, Institute on Community Integration, at the University of Minnesota. The Institute collects these data, with the exception of ICF/MR expenditures, directly from state agencies. The Institute uses ICF/MR expenditure data, compiled by the Medstat Group under contract to HCFA. National data from the Institute were available through 1995. The expenditure and recipient data we report for Florida, Michigan, and Rhode Island were provided to us by the state agencies responsible for developmental services and the Medicaid agencies. The latest complete data available from these three states were for 1994. We therefore used 1994 national data for comparison purposes.

Some differences occur in the recipient counts among the national data we used from the Institute and data we collected from agencies in Florida, Michigan, and Rhode Island. These differences could affect some aspects of our comparisons of national trends and trends in the three states. Institute data on recipients show the total number of persons receiving services on a given date—June 30 of each year—whereas data for the three states show the cumulative number of persons receiving services over a 12-month period. Therefore, data supplied by the states could result in a larger count of program recipients than the methodology used by the Institute. This could have the impact of making per capita expenditure calculations smaller for the state data than for the national data. Our comparisons of data from the two sources, however, showed few substantial differences in the data for the three states.

We excluded children from our analysis because (1) their needs are different in many respects from those of adults, (2) family responsibilities for the care of children are more comprehensive than for adults, and (3) the educational system has the lead public responsibility for services for children. Recipient and expenditure data in this report, however, include some children because it was not possible to systematically exclude them. However, the percentage of children in these services is small. In 1992, for example, about 11 percent of ICF/MR service recipients were less than 21 years old.[15]

We conducted our review from May 1995 through May 1996 in accordance with generally accepted government auditing standards.

---

[15] Robert Prouty, and K. Charlie Lakin, eds., Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1994 (Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration/UAP, The College of Education and Human Development, 1995), p. 113.

Appendix II

Medicaid Waiver Program Services Offered for Persons With Developmental Disabilities in Florida, Michigan, and Rhode Island

States, with HCFA's approval, choose which services they offer through waiver programs and how the services are defined. States can choose from a list of standard services and definitions in the HCFA waiver application or design their own services. In designing their own services, states can add new services or redefine standard services. States can also extend optional services to offer more units of these services to waiver program recipients than are available to other recipients under the regular Medicaid program.

The three states we visited chose to offer a number of standard services under their waiver program. Each state also modified the definition of some standard services that it provides or offered services not on the standard waiver list. (See fig II.1.) For example, Florida modified the definition of case management to include helping individuals and families identify preferences for services. Florida also added several nonstandard, state-defined services such as behavior analysis and assessments and supported living coaching. Rhode Island's modified definition of homemaker services includes a bundle of services often offered separately, including standard homemaker services, personal care services, and licensed practical nursing services. Rhode Island also added nonstandard services to provide minor assistive devices and support of family living arrangements. Michigan modified the standard definition of environmental accessibility adaptations to include not only physical adaptations to the home, but to the work environment as well. Michigan also recently added a new state-defined service, community living supports, which is a consolidation of four services—in-home habilitation, enhanced personal care, personal assistance, and transportation—previously provided separately. Florida and Michigan also chose to offer several optional services in their waiver programs.

Figure II.1: Waiver Program Services Provided in Florida, Rhode Island, and Michigan

Services Used From Standard Waiver List	Florida	Rhode Island	Michigan
Adult Companion Services	☐		
Case Management	■	☐	■
Chore Services	☐		☐
Day Habilitation		☐	☐
Educational Services			☐
Environmental Accessibility Adaptations	☐	■	■
Family Training			☐
Homemaker	☐	■[a]	
Personal Care Services	☐		
Personal Emergency Response System (PERS)	☐		☐
Prevocational Services			☐
Private Duty Nursing	☐		☐
Residential Habilitation	☐	☐	
Respite Care	☐	☐	☐
Skilled Nursing	☐		
Specialized Medical Equipment and Supplies	☐		
Supported Employment Services		☐	☐
Transportation	☐		

Extensions of State Plan Optional Services	Florida	Rhode Island	Michigan
Dental			☐
Enhanced Medical Equipment and Supplies			☐
Occupational Therapy	☐		
Physical Therapy	☐		
Prescribed Drugs			☐
Speech Therapy	☐		
Nonstandard Waiver Services Provided by States			
Behavior Analysis and Assessments	☐		
Community Living Supports			☐
Day Training	☐		
Family Living Arrangements		☐	
Minor Assistive Devices		☐	
Nonresidential Support	☐		
Psychological Services	☐		
Special Medical Home Care	☐		
Specialized Homemaker		☐	
Supported Living Coaching	☐		

☐ Service Offered
■ State Definition Differs From Standard HCFA Definition

---

[a] Rhode Island's definition of homemaker includes not only homemaker services as typically defined, but personal care and licensed practical nursing services as well.

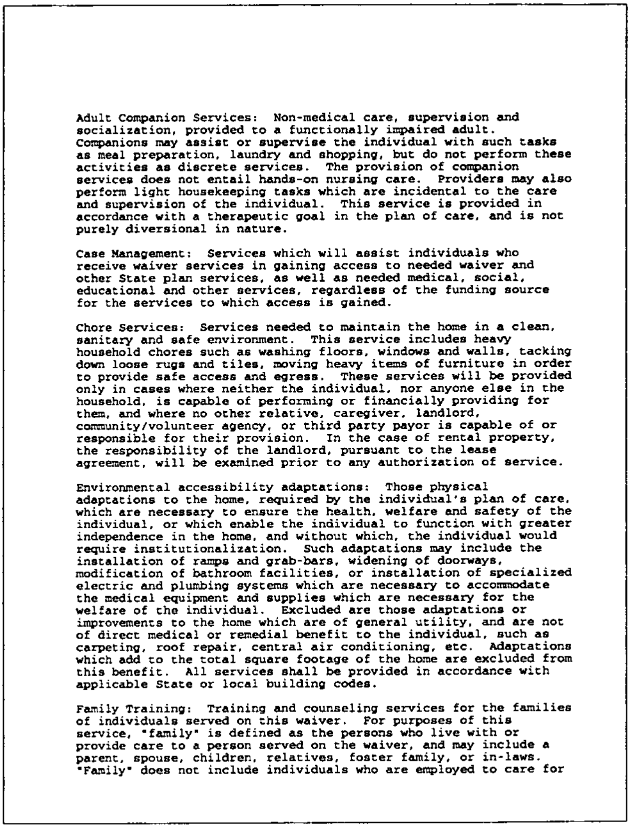
Source: HCFA 1915(c) Waiver Application Format (June 1995) and state waiver applications.

The HCFA definition for each standard waiver service offered in Florida, Michigan, and Rhode Island is shown in appendix III.

Appendix III

Standard Services as Defined in HCFA's 1915(c) Waiver Application Format

This appendix shows HCFA's definition for each standard waiver service offered in Florida, Michigan, and Rhode Island. These service names and definitions are written as they appear in the latest version of the HCFA 1915(c) waiver application format, dated June 1995. Because states have the flexibility to modify these definitions, the definitions and how services are implemented vary among the states.



Adult Companion Services: Non-medical care, supervision and socialization, provided to a functionally impaired adult. Companions may assist or supervise the individual with such tasks as meal preparation, laundry and shopping, but do not perform these activities as discrete services. The provision of companion services does not entail hands-on nursing care. Providers may also perform light housekeeping tasks which are incidental to the care and supervision of the individual. This service is provided in accordance with a therapeutic goal in the plan of care, and is not purely diversional in nature.

Case Management: Services which will assist individuals who receive waiver services in gaining access to needed waiver and other State plan services, as well as needed medical, social, educational and other services, regardless of the funding source for the services to which access is gained.

Chore Services: Services needed to maintain the home in a clean, sanitary and safe environment. This service includes heavy household chores such as washing floors, windows and walls, tacking down loose rugs and tiles, moving heavy items of furniture in order to provide safe access and egress. These services will be provided only in cases where neither the individual, nor anyone else in the household, is capable of performing or financially providing for them, and where no other relative, caregiver, landlord, community/volunteer agency, or third party payor is capable of or responsible for their provision. In the case of rental property, the responsibility of the landlord, pursuant to the lease agreement, will be examined prior to any authorization of service.

Environmental accessibility adaptations: Those physical adaptations to the home, required by the individual's plan of care, which are necessary to ensure the health, welfare and safety of the individual, or which enable the individual to function with greater independence in the home, and without which, the individual would require institutionalization. Such adaptations may include the installation of ramps and grab-bars, widening of doorways, modification of bathroom facilities, or installation of specialized electric and plumbing systems which are necessary to accommodate the medical equipment and supplies which are necessary for the welfare of the individual. Excluded are those adaptations or improvements to the home which are of general utility, and are not of direct medical or remedial benefit to the individual, such as carpeting, roof repair, central air conditioning, etc. Adaptations which add to the total square footage of the home are excluded from this benefit. All services shall be provided in accordance with applicable State or local building codes.

Family Training: Training and counseling services for the families of individuals served on this waiver. For purposes of this service, "family" is defined as the persons who live with or provide care to a person served on the waiver, and may include a parent, spouse, children, relatives, foster family, or in-laws. "Family" does not include individuals who are employed to care for the consumer. Training includes instruction about treatment regimens and use of equipment specified in the plan of care, and shall include updates as necessary to safely maintain the individual at home. All family training must be included in the individual's written plan of care.

Habilitation: Services designed to assist individuals in acquiring, retaining and improving the self-help, socialization and adaptive skills necessary to reside successfully in home and community-based settings. This service includes:

-- Residential habilitation: Assistance with acquisition, retention, or improvement in skills related to activities of daily living, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, and the social and adaptive skills necessary to enable the individual to reside in a non-institutional setting. Payments for residential habilitation are not made for room and board, the cost of facility maintenance, upkeep and improvement, other than such costs for modifications or adaptations to a facility required to assure the health and safety of residents, or to meet the requirements of the applicable life safety code. Payment for residential habilitation does not include payments made, directly or indirectly, to members of the individual's immediate family. Payments will not be made for the routine care and supervision which would be expected to be provided by a family or group home provider, or for activities or supervision for which a payment is made by a source other than Medicaid.

-- Day habilitation: Assistance with acquisition, retention, or improvement in self-help, socialization and adaptive skills which takes place in a non-residential setting, separate from the home or facility in which the individual resides. Services shall normally be furnished 4 or more hours per day on a regularly scheduled basis, for 1 or more days per week unless provided as an adjunct to other day activities included in an individual's plan of care. Day habilitation services shall focus on enabling the individual to attain or maintain his or her maximum functional level and shall be coordinated with any physical, occupational, or speech therapies listed in the plan of care. In addition, they may serve to reinforce skills or lessons taught in school, therapy, or other settings.

-- Prevocational services not available under a program funded under section 110 of the Rehabilitation Act of 1973 or section 602(16) and (17) of the Individuals with Disabilities Education Act (20 U.S.C. 1401 (16 and 17)). Services are aimed at preparing an individual for paid or unpaid employment, but are not job-task oriented. Services include teaching such concepts as compliance, attendance, task completion, problem solving and safety. Prevocational services are provided to persons not expected to be able to join the general work force or participate in a transitional sheltered workshop within one year (excluding supported employment programs). Prevocational services are available only to individuals who have previously been discharged from a SNF [skilled nursing facility], ICF [intermediate care facility], NF [nursing facility] or ICF/MR [intermediate care facility for mental retardation]. Activities included in this service are not primarily directed at teaching specific job skills, but at underlying habilitative goals, such as attention span and motor skills. All prevocational services will be reflected in the individual's plan of care as directed to habilitative, rather than explicit employment objectives.

-- Educational services, which consist of special education and related services as defined in sections (15) and (17) of the Individuals with Disabilities Education Act, to the extent to which they are not available under a program funded by IDEA.

-- Supported employment services, which consist of paid employment for persons for whom competitive employment at or above the minimum wage is unlikely, and who, because of their disabilities, need intensive ongoing support to perform in a work setting. Supported employment is conducted in a variety of settings, particularly work sites in which persons without disabilities are employed. Supported employment includes activities needed to sustain paid work by individuals receiving waiver services, including supervision and training. When supported employment services are provided at a work site in which persons without disabilities are employed, payment will be made only for the adaptations, supervision and training required by individuals receiving waiver services as a result of their disabilities, and will not include payment for the supervisory activities rendered as a normal part of the business setting. Supported employment services furnished under the waiver are not available under a program funded by either the Rehabilitation Act of 1973 or P.L. 94-142.

Homemaker: Services consisting of general household activities (meal reparation and routine household care) provided by a trained homemaker, when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for him or herself or others in the home. Homemakers shall meet such standards of education and training as are established by the State for the provision of these activities.

Personal care services: Assistance with eating, bathing, dressing, personal hygiene, activities of daily living. This service may include assistance with preparation of meals, but does not include the cost of the meals themselves. When specified in the plan of care, this service may also include such housekeeping chores as bedmaking, dusting, and vacuuming, which are incidental to the care furnished, or which are essential to the health and welfare of the individual, rather than the individual's family. Personal care providers must meet State standards for this service.

Personal Emergency Response Systems (PERS): PERS is an electronic device which enables certain individuals at high risk of institutionalization to secure help in an emergency. The individual may also wear a portable "help" button to allow for mobility. The system is connected to the person's phone and programmed to signal a response center once a "help" button is activated. The response center is staffed by trained professionals. PERS services are limited to those individuals who live alone, or who are alone for significant parts of the day, and have no regular caregiver for extended periods of time, and who would otherwise require extensive routine supervision.

Private duty nursing: Individual and continuous care (in contrast to part time or intermittent care) provided by licensed nurses within the scope of State law. These services are provided to an individual at home.

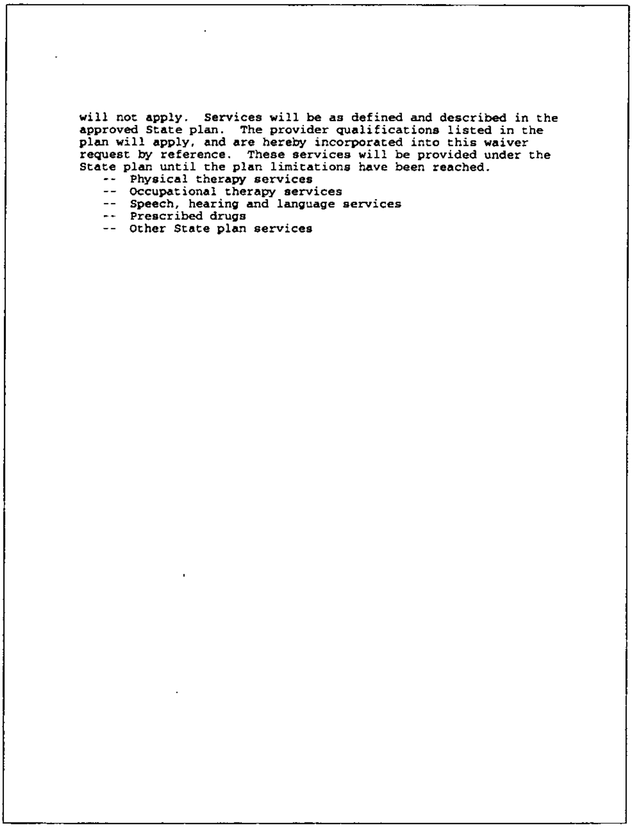
Respite care: Services provided to individuals unable to care for themselves; furnished on a short-term basis because of the absence or need for relief of those persons normally providing the care.

Skilled nursing: Services listed in the plan of care which are within the scope of the State's Nurse Practice Act and are provided by a registered professional nurse, or licensed practical or vocational nurse under the supervision of a registered nurse, licensed to practice in the State.

Specialized Medical Equipment and Supplies: Specialized medical equipment and supplies include devices, controls, or appliances, specified in the plan of care, which enable individuals to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with the environment in which they live. This service also includes items necessary for life support, ancillary supplies and equipment necessary to the proper functioning of such items, and durable and non-durable medical equipment not available under the Medicaid State plan. Items reimbursed with waiver funds shall be in addition to any medical equipment and supplies furnished under the State plan and shall exclude those items which are not of direct medical or remedial benefit to the individual. All items shall meet applicable standards of manufacture, design, and installation.

Transportation: Service offered in order to enable individuals served on the waiver to gain access to waiver and other community services, activities and resources, specified by the plan of care. This service is offered in addition to medical transportation required under 42 CFR 431.53 and transportation services under the State plan, defined at 42 440.170(a) (if applicable), and shall not replace them. Transportation services under the waiver shall be offered in accordance with individual's plan of care. Whenever possible, family neighbors, friends, or community agencies which can provide this service without charge will be utilized.

Extended State plan services: The following services, available through the approved State plan, will be provided, except that the limitations on amount, duration and scope specified in the plan



will not apply. Services will be as defined and described in the approved State plan. The provider qualifications listed in the plan will apply, and are hereby incorporated into this waiver request by reference. These services will be provided under the State plan until the plan limitations have been reached.
-- Physical therapy services
-- Occupational therapy services
-- Speech, hearing and language services
-- Prescribed drugs
-- Other State plan services

Licensure, Certification, and Other Standards for Waiver Program Services

HCFA requires that each state specify licensure, certification, or other standards for each service in its waiver application. These requirements are detailed in state and local laws, regulations, or operating guidelines and enforced by state and local agencies. Such requirements may include professional standards for individuals providing services, minimum training requirements, criminal background checks, certification for facilities, local building codes, and fire and health requirements. For example, the information below shows how Florida addresses HCFA requirements for licensure, certification, and other standards for each of its waiver program services. The information, unless otherwise noted, was obtained from Florida's Department of Health and Rehabilitative Services' July 1995 Services Directory, which provides the details of service standards in Florida's approved waiver.[16]

Services

Behavioral Analysis and Assessment

Provider Types	Psychologists, clinical social workers, marriage and family therapists, mental health counselors, or providers certified by the Department of Health and Rehabilitative Services (HRS) Developmental Services (DS) Behavior Analysis Certification program.
Licensure/Registration	Psychologists shall be licensed by the Department of Business and Professional Regulation in accordance with Chapter 490, Florida statutes (F.S.). Clinical social workers, marriage and family therapists, and mental health counselors shall be licensed in accordance with Chapter 491, F.S. Others must be certified under the HRS Behavior Analysis Certification program.
Other Standards	Background screening is required for those certified under the HRS Developmental Services Behavior Analysis Certification program.

---

[16] All providers of Developmental Services (DS) waiver services must be certified by the district level Department of Health and Rehabilitative Services (HRS) DS program office.

Chore

Provider Types	Home health agencies, hospice agencies, and independent vendors.
Licensure/Registration	Home health and hospice agencies must be licensed by the Agency for Health Care Administration. In accordance with Chapter 400, Part IV or Part VI, F.S. Independent vendors are not required to be licensed or registered.
Other Standards	Independent vendors must have at least 1 year of experience working in a medical, psychiatric, nursing, or child care setting or working with developmentally disabled persons. College or vocational/technical training, equal to 30 semester hours, 45 quarter hours, or 720 classroom hours can substitute for the required experience. Background screening required of independent vendors.

Companion

Provider Types	Home health agencies, hospice agencies, and independent vendors.
Licensure/Registration	Home health and hospice agencies shall be licensed by the Agency for Health Care Administration, Chapter 400, Part IV or Part VI, F.S. Independents shall be registered with the Agency for Health Care Administration as companions or sitters in accordance with Section 400.509, F.S.
Other Standards	Background screening required for independent vendors.

Day Training (Adult)

Provider Types	Centers or sites designated by the district DS office as adult day training centers.
Licensure/Registration	Licensure/registration is not required.
Other Standards	Background screening required for all direct care staff.

Environmental Modifications

Provider Types	Contractors, electricians, plumbers, carpenters, handymen, medical supply companies, and other vendors.
Licensure/Registration	Contractors, plumbers, and electricians will be licensed by the Department of Business and Professional Regulation in accordance with Chapter 489, F.S. Medical supply companies, carpenters, handymen, and other vendors shall hold local occupational licenses or permits in accordance with Chapter 205, F.S.
Other Standards	None.

Homemaker

Provider Types	Home health agencies, hospice agencies, and independent vendors.
Licensure/Registration	Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S. Independent vendors must be registered as homemakers with the Agency for Health Care Administration in accordance with Section 400.509, F.S.
Other Standards	Background screening required for independents.

Nonresidential Support

Provider Types	Independent vendors and agencies.
Licensure/Registration	Licensure/registration is not required.
Other Standards	Independent vendors must have at least 1 year of experience working in a medical, psychiatric, nursing, or child care setting or in working with developmentally disabled persons. College or vocational/technical training that equals at least 30 semester hours, 45 quarter hours, or 720 classroom hours may substitute for the required experience. Agency employees providing this service must meet the same requirements. Background

screening required of agency employees who perform this service and of independent vendors.

Occupational Therapy and Assessment

Provider Types	Occupational therapists, occupational therapy aides, and occupational therapy assistants. Occupational therapists, aides, and assistants may provide this service as independent vendors or as employees of licensed home health or hospice agencies.
Licensure/Registration	Occupational therapists, occupational therapy aides, and occupational therapy assistants shall be licensed by the Department of Business and Professional Regulation in accordance with Chapter 468, Part III, F.S. and may perform services only within the scope of their licenses. Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S.
Other Standards	None.

Personal Care Assistance

Provider Types	Home health and hospice agencies and independent vendors.
Licensure/Registration	Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S. Independent vendors are not required to be licensed or registered.
Other Standards	Independent vendors shall have at least 1 year of experience working in a medical, psychiatric, nursing, or child care setting or working with developmentally disabled persons. College or vocational/technical training that equals at least 30 semester hours, 45 quarter hours, or 720 classroom hours may substitute for the required experience. Background screening is required of independent vendors.

Personal Emergency Response System (PERS)

Provider Types	Electrical contractors and alarm system contractors.
Licensure/Registration	Electrical contractors and alarm system contractors must be licensed by the Department of Business and Professional Regulation in accordance with Chapter 489, Part II, F.S.
Other Standards	None.

Physical Therapy and Assessment

Provider Types	Physical therapist and physical therapist assistants. Physical therapist and assistants may provide this service as independent vendors or as employees of licensed home health or hospice agencies.
Licensure/Registration	Physical therapists and therapist assistants shall be licensed by the Department of Business and Professional Regulation in accordance with Chapter 486, F.S., and may perform services only within the scope of their licenses. Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S.
Other Standards	None.

Private Duty Nursing

Provider Types	Registered nurses and licensed practical nurses. Nurses may provide this service as independent vendors or as employees of licensed home health or hospice agencies.
Licensure/Registration	Nurses shall be registered or licensed by the Department of Business and Professional Regulation in accordance with Chapter 464, F.S. Home health or hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S.
Other Standards	None.

Psychological Services

Provider Types	Psychologists.
Licensure/Registration	Psychologists shall be licensed by the Department of Business and Professional Regulation, Chapter 490, F.S.
Other Standards	None.

Residential Habilitation

Provider Types	Group homes, foster homes, and adult congregate living facilities and independent vendors.
Licensure/Registration	Group and foster homes facilities shall be licensed by the Department of Health and Rehabilitative Services in accordance with Chapter 393, F.S. Adult congregate living facilities shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part III, F.S. Licensure or registration is not required for independent vendors.
Other Standards	Independent vendors must possess at least an associate's degree from an accredited college with a major in nursing; education; or a social, behavioral, or rehabilitative science. Experience in one of these fields shall substitute on a year-for-year basis for required education. Background screening required of direct care staff employed by licensed residential facilities and independent vendors.

Respite Care

Provider Types	Group homes; foster homes; adult congregate living facilities; home health agencies; hospice agencies; other agencies that specialize in serving persons who have a developmental disability; and independent vendors, registered nurses, and licensed practical nurses.
Licensure/Registration	Group and foster homes shall be licensed by the Department of Health and Rehabilitative Services in accordance with Chapter 393, F.S. Adult congregate living facilities shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part III, F.S. Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S.

Nurses who render the service as independent vendors shall be licensed or registered by the Department of Business and Professional Regulation in accordance with Chapter 464, F.S. Licensure or registration is not required for independent vendors who are not nurses.

Other Standards	Background screening is required of direct care staff employed by licensed residential facilities and other agencies that serve persons who have a developmental disability and of independent vendors who are not registered or licensed practical nurses. Independent vendors who are not nurses must have at least 1 year of experience working in a medical, psychiatric, nursing, or child care setting or working with developmentally disabled persons. College or vocational/technical training that equals at least 30 semester hours, 45 quarter hours, or 720 classroom hours may substitute for the required experience.

Skilled Nursing Care

Provider Types	Registered nurses and licensed practical nurses. Nurses may provide this service as independent vendors or as employees of licensed home health or hospice agencies.
Licensure/Registration	Nurses shall be registered or licensed by the Department of Business and Professional Regulation in accordance with Chapter 464, F.S. Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S.
Other Standards	None.

Special Medical Home Care

Provider Types	Group homes that employ registered nurses, licensed practical nurses, or licensed nurse aides.
Licensure/Registration	Group homes shall be licensed by the Department of Health and Rehabilitative Services in accordance with Chapter 393, F.S. Nurses shall be registered or licensed by the Department of Business and Professional Regulation in accordance with Chapter 464, F.S. and may perform services only within the scope of their license or registration.

Other Standards	Background screening required of direct care staff employed by licensed group homes.

Specialized Medical Equipment and Supplies

(See Florida's approved waiver renewal application for 1993-98.)

Provider Types	Medical supply companies, licensed pharmacies, and independent vendors.
Licensure/Registration	Pharmacies must be licensed by the Department of Business and Professional Regulation in accordance with Chapter 465, F.S. Medical supply companies and independent vendors must be licensed under Chapter 205, F.S.
Other Standards	None.

Speech Therapy and Assessment

Provider Types	Speech-language pathologists and speech-language pathology assistants. Speech-language pathologists or assistants may provide this service as independent vendors or as employees of licensed home health or hospice agencies.
Licensure/Registration	Speech-language pathologists and pathology assistant shall be licensed by the Department of Business and Professional Regulation in accordance with Chapter 468, Part I, F.S. Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S.
Other Standards	None.

Support Coordination (Case Management)

Provider Types	Single practitioner vendors or agency vendors.
Licensure/Registration	Licensure is not required.

Other Standards	Single practitioners and support coordinators employed by agencies shall have a bachelor's degree from an accredited college or university and 2 years of professional experience in mental health, counseling, social work, guidance, or health and rehabilitative programs. A master's degree shall substitute for 1 year of the required experience. Providers (single practitioners and agency directors/managers) are required to complete statewide training conducted by the Developmental Services Program Office, as well as district-specific training conducted by the district DS office. Support coordinators employed by agencies are also required to be trained on the same topics covered in the statewide and district-specific training; however, this training may be conducted by the support coordination agency if approved by the district and the agency trainer meets specific requirements described in Chapter 10F-13, Florida Administrative Code.

Supported Living Coaching

Provider Types	Independent vendors and agency vendors.
Licensure/Registration	Licensure is not required.
Other Standards	Independent vendors and employees of agencies who render this service shall have a bachelor's degree from an accredited college or university with a major in nursing; education; or a social, behavioral, or rehabilitative science or shall have an associate's degree from an accredited college or university with a major in nursing; education; or a social, behavioral, or rehabilitative science and 2 years of experience. Experience in one of these fields shall substitute on a year-for-year basis for the required college education. Agency employees are required to attend at least 12 hours of preservice training and independent vendors must attend at least one supported living-related conference or workshop before certification. All providers and employees are also required to attend human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) training. Background screening is required.

Transportation

Provider Types	Independent vendors and commercial transportation agencies.

Licensure/Registration	Providers shall hold applicable licenses issued by the Department of Highway Safety and Motor Vehicles and shall secure appropriate insurance. Proof of license and insurance shall be provided to the district DS office.
Other Standards	Background screening required for independent vendors.

Related GAO Products

Medicaid Long-Term Care: State Use of Assessment Instruments in Care Planning (GAO/PEMD-96-4, Apr. 2, 1996).

Long-Term Care: Current Issues and Future Directions (GAO/HEHS-95-109, Apr. 13, 1995).

Medicaid: Spending Pressures Drive States Toward Program Reinvention (GAO/HEHS-95-122, Apr. 4, 1995).

Long-Term Care: Diverse, Growing Population Includes Millions of Americans of All Ages (GAO/HEHS-95-26, Nov. 7, 1994).

Long-Term Care Reform: States' Views on Key Elements of Well-Designed Programs for the Elderly (GAO/HEHS-94-227, Sept. 6, 1994).

Long-Term Care: Other Countries Tighten Budgets While Seeking Better Access (GAO/HEHS-94-154, Aug. 30, 1994).

Financial Management: Oversight of Small Facilities for the Mentally Retarded and Developmentally Disabled (GAO/AIMD-94-152, Aug. 12, 1994).

Medicaid Long-Term Care: Successful State Efforts to Expand Home Services While Limiting Costs (GAO/HEHS-94-167, Aug. 11. 1994).

Long-Term Care: Status of Quality Assurance and Measurement in Home and Community Based Services (GAO/PEMD-94-19, Mar. 31, 1994).

Long-Term Care: Support for Elder Care Could Benefit the Government Workplace and the Elderly (GAO/HEHS-94-64, Mar. 4, 1994).

Long-Term Care: Private Sector Elder Care Could Yield Multiple Benefits (GAO/HEHS-94-60, Jan. 31, 1994).

Health Care Reform: Supplemental and Long-Term Care Insurance (GAO/T-HRD-94-58, Nov. 9, 1993).

Long-Term Care Reform: Rethinking Service Delivery, Accountability, and Cost Control (GAO/HRD-93-1-SP, July 13, 1993).

United States General Accounting Office

GAO

Report to the Ranking Minority Member, Committee on Government Reform and Oversight, House of Representatives

October 1997

MEDICAID MANAGED CARE

Delays and Difficulties in Implementing California's New Mandatory Program

GAO/HEHS-98-2

GAO

United States
General Accounting Office
Washington, D.C. 20548

Health, Education, and
Human Services Division

B-276078

October 1, 1997

The Honorable Henry A. Waxman
Ranking Minority Member
Committee on Government Reform
and Oversight
House of Representatives

Dear Mr. Waxman:

California's Medicaid program, Medi-Cal, served 5.2 million beneficiaries—almost one-seventh of Medicaid beneficiaries nationwide—at a cost of nearly $18 billion in federal, state, and local Medicaid funds in fiscal year 1996. Over the past 2 decades, Medi-Cal has increasingly relied on managed care delivery systems with the aim of improving beneficiary access to quality care while reducing the rate of program cost growth. In 1992, California began planning a major expansion of its Medi-Cal managed care program—one that would eventually require more than 2.2 million beneficiaries in 12 counties to enroll in one of two managed care plans participating in each county.

In a 1995 report, we expressed concern about California's ability to successfully carry out such an expansion because of several weaknesses that we identified in the Medi-Cal managed care program, including the state's potential inability to effectively monitor its contracts with managed care plans and to ensure that the services that plans were contracted to provide were actually provided.[1] Now, nearly 5 years after planning began, the state has repeatedly delayed its completion date for full implementation of the expansion.

In light of these delays and the magnitude of the state's Medicaid program, you asked us to follow up on our earlier report and (1) determine the implementation status of California's managed care expansion, including identifying the primary causes of delays; (2) assess the degree to which state efforts to educate beneficiaries about their managed care options and enroll them in managed care have encouraged beneficiaries to choose a plan; (3) evaluate the management of the state's education and enrollment process for the new program, including state and federal oversight of enrollment brokers that the state contracted with to carry out these functions; and (4) make an initial assessment of the impact of the managed

---

[1] Medicaid Managed Care: More Competition and Oversight Would Improve California's Expansion Plan (GAO/HEHS-95-87, Apr. 28, 1995).

care expansion on current safety-net providers, such as community health centers, that serve low-income beneficiaries.

To conduct our work, we interviewed officials from California's Department of Health Services (DHS); DHS' former and current enrollment brokers; selected managed care plans and advocacy groups; and the Department of Health and Human Services' Health Care Financing Administration (HCFA), which oversees the Medicaid program. We also reviewed relevant state statutes and regulations and DHS policies and procedures on the education and enrollment process, as well as the enrollment broker contracts. For more detailed information on our scope and methodology, see the appendix.

Results in Brief

Despite California's extensive planning and managed care experience, implementation of its 12-county expansion program is more than 2 years behind its initial schedule and is still incomplete. California originally had planned to implement the program simultaneously in all affected counties by March 1995. However, as a number of unforeseen difficulties arose, such as in contracting with and developing managed care plans, the state began to stagger implementation as it became clear that some counties would be ready before others. Still, as of July 1997, the program had been fully implemented in only seven counties. The most recent schedule estimated complete implementation in all 12 counties by December 1997, at the earliest.

The state's efforts to encourage beneficiaries to choose a health plan have been undermined by problems in the process for educating and enrolling beneficiaries. According to HCFA, beneficiary and provider advocates, and managed care plans, a number of problems contributed to confusion for many beneficiaries, including incorrect or unclear information about the mandatory Medi-Cal program and participating plans as well as erroneous assignments of beneficiaries to plans. Officials from one plan said that beneficiaries did not understand the changes in their health care coverage, and some beneficiaries thought that they were losing Medi-Cal benefits altogether. Available data show that, on average, almost half of affected beneficiaries have not actively chosen their own plan but instead have been automatically assigned to one by the state.

Other problems were evident in DHS' management of the program, such as insufficient performance standards for the enrollment brokers that DHS had contracted with to provide information to beneficiaries about their managed care options and enroll them in the Medi-Cal program. The enrollment brokers also believed that difficult operating conditions—such as continual changes in state program and policy directives—contributed to the implementation problems. Poor internal communication and weak ties with advocacy and community-based organizations further exacerbated the difficulties DHS encountered in implementing its mandatory managed care program.

California has taken a number of actions to improve the implementation and administration of its mandatory expansion program. For example, DHS has begun translating into a number of different languages and redesigning the enrollment materials to make them more comprehensible and has instituted on-site monitoring of the enrollment broker's processes for enrolling beneficiaries. DHS also has taken steps to work more closely with community-based organizations to improve outreach efforts. However, these actions were taken too late to benefit the many beneficiaries who have already enrolled in the seven counties where full program implementation has been completed. And problems persist—some serious enough to have prompted HCFA to delay full implementation of the program in several counties earlier this year. HCFA is in the process of developing federal guidelines on designing and implementing an education and enrollment program. But these guidelines are not expected to be available before October 1997—too late to help influence design and early implementation issues for California's program.

Despite the fact that the state's 12-county expansion program was designed to help ensure that federally qualified health centers, community and rural health centers, and other safety-net providers participate in the provider networks, some safety-net providers have reported difficulty maintaining their patient base. Though the new mandatory program provides some assurances that health plans assign beneficiaries to safety-net providers, it does not guarantee these providers any specified level of enrollments. Many beneficiaries who have chosen a primary care physician have opted to select a provider other than a participating safety-net provider.

Background

Medi-Cal was implemented in 1965; the year the Medicaid statute was enacted.[2] Administered by the California DHS,[3] in fiscal year 1996, Medi-Cal provided a wide range of services to approximately 5.2 million low-income individuals at an estimated cost of about $17.7 billion—about 11 percent of national Medicaid expenditures. Medi-Cal managed care, which is composed of several programs, including the 12-county expansion program, is expected to serve over 3 million Medi-Cal beneficiaries once fully implemented.

Since 1968, the state has contracted with prepaid health plans (PHP)—California's equivalent of the federal definition of "health maintenance organizations"—to provide, on a capitated basis, preventive and acute-care Medicaid services, as well as case management. In the 1980s, the state established three additional managed care programs: Primary Care Case Management (PCCM), County Organized Health System (COHS), and Geographic Managed Care (GMC).[4] In early 1993, the state completed conceptual development of its most ambitious program to date: the "two-plan model," which requires more than 2.2 million Medi-Cal beneficiaries to enroll with one of two health plans participating in each of 12 counties.[5]

---

[2] Established under title XIX of the Social Security Act, Medicaid finances health care for about 37 million low-income families, and aged, blind, and disabled individuals nationwide. Jointly funded by the federal government and the states, Medicaid is administered by states within broad federal guidance.

[3] DHS determines policy, establishes fiscal and management controls, contracts with managed care plans, and reviews program activities.

[4] PCCMs, operated primarily by physicians and physician groups, contract with the state to provide certain outpatient health care services for a capitated fee. Services not capitated are available to beneficiaries on a fee-for-service basis. COHSs—which operate in San Mateo, Santa Barbara, Solano, Orange, and Santa Cruz counties—are local entities that contract with DHS to administer a capitated, comprehensive, case-managed health care delivery system. Under the GMC model—currently operating in Sacramento County and planned for San Diego County—the state contracts directly with several managed care plans to provide covered services to beneficiaries on a capitated basis. PCCM enrollment is voluntary; COHS enrollment is mandatory for all Medicaid-eligible populations; and GMC enrollment is mandatory for Aid to Families With Dependent Children (AFDC) and AFDC-related beneficiaries. As of April 1997, about 1.2 million beneficiaries were enrolled in the PHP, PCCM, COHS, and GMC programs.

[5] In January 1996, HCFA approved California's request under section 1915(b) of the Social Security Act to waive three sections of the act. Section 1902(a), which requires a Medicaid program to be available throughout the state, was waived, enabling the state to implement the two-plan model in selected counties only. Section 1902(a)(10)(B), comparability of services, was waived, enabling the state to offer additional benefits not available to Medi-Cal beneficiaries not enrolled in the two-plan model. And section 1902(a)(23), freedom of choice, was waived, enabling the state to restrict beneficiary choice of providers under the two-plan model and to require certain beneficiaries to enroll. The 2-year, renewable waiver expires January 22, 1998.

The Two-Plan Model

California's managed care expansion program—often referred to as the two-plan model—was designed to ensure that each of the two managed care plans operating in each county could achieve an enrollment level sufficient to spread risk and that beneficiaries could obtain care from health plans that also served privately insured individuals. In addition, the model was developed to make the most of limited state resources by restricting the number of plans the state would need to monitor.

Selection of the 12 counties to use the two-plan model was made on the basis of two criteria.[6] First, the counties must have had a minimum of 45,000 Medicaid beneficiaries eligible to participate in managed care,[7] and, second, the counties must have had an interest in the program or a significant managed care presence already established in the county. (See table 1 for the number of eligibles and current enrollees by county and plan.)

---

[6] The 12 counties are Alameda, Contra Costa, Fresno, Kern, Los Angeles, Riverside, San Bernardino, San Francisco, San Joaquin, Santa Clara, Stanislaus, and Tulare.

[7] Former AFDC and AFDC-related beneficiaries are required to enroll in the two-plan model. Supplemental Security Income (SSI) and SSI-related beneficiaries may enroll in managed care plans on a voluntary basis. California will continue to use this eligibility criteria until the Governor and state legislature agree on an approach to determining eligibility under the new Temporary Assistance for Needy Families (TANF) program, which replaced AFDC.

Table 1: Medi-Cal Eligibles and Enrollees by County and Plan

	Eligibles as of April 1997			Health plans	
Two-plan counties	Mandatory	Nonmandatory	Enrollees as of July 1997	Names of plans	Dates of initial operation
Alameda	116,934	61,105	73,535	Alameda Alliance for Health	1/1/96
			25,440	Blue Cross of California	7/1/96
Contra Costa	55,431	27,734	42,706	Contra Costa Health Plan	2/1/97
			3,392	Foundation Health Systems	3/1/97
Fresno	145,558	44,352	105,015	Blue Cross of California	11/1/96
			17,429	Foundation Health Systems	1/1/97
Kern	102,639	30,606	53,212	Kern Family Health Care	7/1/96
			23,195	Blue Cross of California	9/1/96
Los Angeles	1,119,120	435,208	191,964	LA Care	4/1/97
			256,812	Foundation Health Systems	7/1/97
Riverside and San Bernardino	368,588	106,249	130,624	Inland Empire Health Plan	9/1/96
			N/A	Molina Medical Centers	Unknown
San Francisco	44,155	58,408	23,079	San Francisco Health Plan	1/1/97
			15,585	Blue Cross of California	7/1/96
San Joaquin	84,383	29,427	59,199	Health Plan of San Joaquin	2/1/96
			11,329	OMNI	2/1/97
Santa Clara	97,815	51,029	42,917	Santa Clara Health	2/1/97
			34,466	Authority Blue Cross of California	10/1/96
Stanislaus	63,901	21,410	N/A	Blue Cross of California (as local initiative)	10/1/97
			9,145	OMNI	2/1/97
Tulare	71,608	19,945	N/A	MediCo	4th quarter 1997
			N/A	Foundation Health Systems	4th quarter 1997
Total	**2,270,132**	**885,473**	**1,119,044**		

Note: N/A = not applicable.

In each county, beneficiaries are required to enroll in either the "local initiative"—a publicly sponsored health plan cooperatively developed by local government, clinics, hospitals, and other providers—or the commercial plan, under contract in a beneficiary's county of residence.[8] The local initiative concept was developed to support health care safety-nets—those providers, such as community health centers and federally qualified health centers, that provide health care services to the indigent. Minimum enrollment levels were set for both the commercial and local initiative plans to ensure their financial viability. A maximum enrollment level was also set for each commercial plan to further protect local initiatives and their subcontracted safety-net providers. The state

---

[8] Fresno County did not develop a local initiative, so Fresno has two commercial plans.

contracted with the local initiatives on a sole-source basis, while the commercial plan contracts were awarded on a competitive basis.

The situation in Los Angeles County, however, is unique. While California contracted with a local initiative and a commercial plan in Los Angeles County, the county has, in essence, 10 plans because the local initiative plan subcontracted with 7 plans, and the commercial plan subcontracted with 2 plans.[9] Beneficiaries can choose a primary care physician from any one of the 10 plans.

Health Care Options Program Educates and Enrolls Beneficiaries

Medi-Cal beneficiaries required to enroll in the two-plan expansion program are informed about managed care and their choices of health care plans through DHS' Health Care Options (HCO) program. HCO also enrolls and disenrolls beneficiaries in managed care plans.[10] The state contracts with an enrollment broker to conduct HCO program activities.

Beneficiaries are informed about the mandatory expansion program and their available choices primarily through an enrollment packet that they receive through the mail. The enrollment packet includes information on managed care, how to join a health plan, available plans and participating providers, phone numbers to call for assistance, and an enrollment form. The packet also includes the first of three standard notices that inform beneficiaries of the 30-day time frame in which they have to choose a plan and the plan to which they will be automatically assigned if they do not return an enrollment form.[11]

Beneficiaries also can learn about the two-plan model and their plan options at HCO presentations, which are often held daily at county social service offices. At these face-to-face presentations, HCO counselors provide information on managed care, plans available in the county, how to fill out

---

[9] The plan partners in the local initiative—LA Care—are Blue Cross, Care 1st, LA Community Health Plan, Maxicare, United Health Plan, Tower, and Kaiser Foundation Health Plan. The plan partners in the commercial plan—Foundation Health Systems—are Universal Care and Molina Medical Centers. Unlike Foundation Health Systems, LA Care does not directly provide health care services.

[10] DHS' Medi-Cal Managed Care and Payment Systems divisions share responsibility for the HCO program. The Medi-Cal Managed Care Division makes all policy decisions regarding the program, while the Payment Systems Division implements and manages the HCO program and monitors HCO activities, which are contracted to an enrollment broker. The Payment Systems Division assumed this responsibility from the Medi-Cal Managed Care Division in March 1997.

[11] The state assigns beneficiaries according to an established methodology, which generally stipulates that once the local initiative reaches a minimum number of enrollments, the state would assign every other beneficiary who did not choose a plan to the commercial plan. Beneficiaries who were already enrolled in one of the plans operating under the two-plan model are not re-assigned by the state. Beneficiaries have the option to change plans at any time.

the enrollment form, beneficiary rights and responsibilities, how to resolve problems with plans, and who to contact for more information. Enrollment materials are available at the presentations. Beneficiaries also can contact HCO's toll-free call center to obtain enrollment packets and to have enrollment-related questions or concerns addressed.

Since 1984, DHS has contracted with an enrollment broker to provide certain education and enrollment services.[12] Initially, enrollment broker responsibilities consisted primarily of conducting HCO presentations in selected counties and helping beneficiaries complete enrollment forms. With the expansion of Medi-Cal's mandatory program, broker responsibilities increased. In addition to distributing enrollment packets and providing HCO presentations, the broker was tasked with processing beneficiary enrollments and disenrollments in 18 counties with managed care and operating a call center to assist beneficiaries.

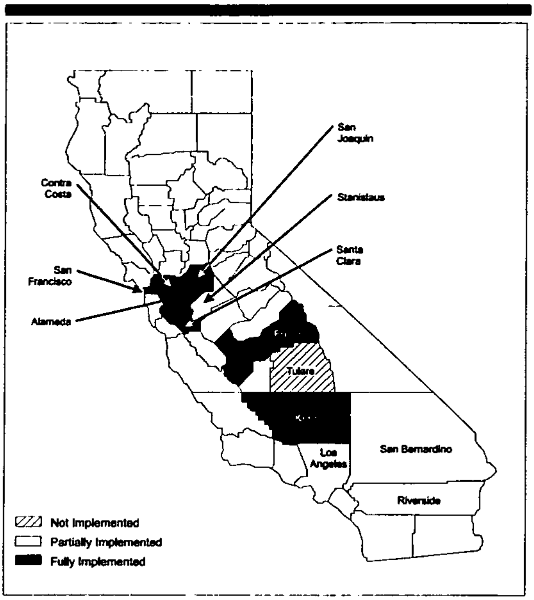
Implementation of Expansion Program Is More Than 2 Years Behind Initial Schedule

Full implementation of Medi-Cal's mandatory expansion program is more than 2 years behind its initial implementation schedule. Originally, local initiatives and commercial plans in each of the 12 affected counties were to become simultaneously operational in March 1995. However, repeated delays in the awarding of contracts and the development of plans made it clear that some counties would be ready for implementation before others. Implementation therefore took place county by county. As of July 1997, plans in 7 of the 12 affected counties had been fully implemented, and full implementation in all counties was scheduled for the end of 1997 at the earliest. Figure 1 shows the 12 counties and their stages of implementation. As of July 1997, over 1.1 million beneficiaries were enrolled in the 12-county expansion program.

---

[12] Between October 1991 and December 1996, Medi-Cal contracted with an Oregon-based enrollment broker, Benova, formerly HealthChoice, Inc. In 1996, the enrollment broker contract was re-bid and awarded to Virginia-based Maximus, which began operations January 1, 1997.

Figure 1: 12 Counties Participating in the Expansion Program and Their Stages of Implementation as of July 1997



Overly optimistic time frames and unanticipated difficulties resulted in a number of delays throughout the state's planning and awarding of managed care contracts. Developing a Request for Applications for commercial plans and a Detailed Design Application for local initiatives took several months longer than expected. Once applications were submitted, the state did not at first meet its 90-day turnaround goal for approving submissions. Some plans protested the contract awards, further delaying the contracting process 6 to 8 months. In addition, the state unexpectedly had to obtain—at the request of the developers of the local initiatives—additional state legislative authority, such as exemptions from regulations on public meetings that would enable the local initiatives to hold closed-door sessions to negotiate rates with providers.

There also were delays in establishing local initiatives and commercial plans. Some local initiatives took 3 years to develop, instead of the expected 2 years. Unlike commercial plans, local initiatives had to develop health care plans from scratch and, as public entities, they had to interact with community stakeholders. In Fresno County, consensus on whether or not to develop a local initiative could not be reached. As a result, no local initiative was developed, and the state awarded a second commercial contract. The local government in Stanislaus County also had difficulty establishing a local initiative. Consequently, the local initiative contract was awarded to a commercial plan, which will operate in informal partnership with the county. It also took longer than expected for some commercial plans to begin operating under the two-plan model. In addition to obtaining approval of material modifications to their operating licenses, commercial plans had to develop provider networks in counties where the plans were not already operating.

Even after implementation of the expansion program began—with Alameda County in January 1996—the state and HCFA took actions that further delayed implementation. For example, DHS delayed full implementation of the program in Fresno, Contra Costa, San Joaquin, and Santa Clara counties to allow the new enrollment broker to fully test its automated systems and capacity to handle all of the enrollment and disenrollment functions. Because of concerns about the education and enrollment process in Santa Clara, San Joaquin, and Los Angeles counties, HCFA temporarily prohibited the automatic assignment of beneficiaries who did not choose a plan and required DHS instead to maintain them in the fee-for-service system. As a result, the pace of enrollment was slowed in these counties, even though plans were allowed to receive voluntary enrollments.

As of July 1997, the expansion program had been fully implemented in seven counties—Alameda, Kern, Fresno, San Francisco, Santa Clara, San Joaquin, and Contra Costa—with beneficiaries required to enroll in either the local initiative or the commercial plan. In four of the remaining counties—San Bernardino, Riverside, Stanislaus, and Los Angeles—the program was partially implemented, with only one plan operating in San

Bernardino, Riverside, and Stanislaus counties. Although Los Angeles County had both plans operating, the program was in effect only partially implemented because HCFA had delayed automatic assignment and the state had prohibited additional enrollment in the commercial plan until some remaining contract issues were resolved. In Tulare County, neither plan was operating.

The December 1997 target date for full implementation may not be met since some of the plans in counties where the program has yet to be fully implemented have had difficulty developing and complying with regulations. For example, although both plans in Tulare County were tentatively scheduled to become operational by the end of the year, the plans were having difficulty organizing provider networks; implementation target dates have already been moved from spring 1997 to the end of the year. In San Bernardino and Riverside counties, the local initiative began operating in September 1996, but the commercial plan's operation was delayed because it had not complied with the federal Medicaid requirement that effectively prohibited plan enrollment of Medicaid beneficiaries from reaching 75 percent.[13] This requirement was repealed in August 1997; however, because of concerns the state has with other aspects of the plan's operations, it is still not clear when this plan will begin operating under the two-plan model.

Education and Enrollment Problems Contributed to Low Beneficiary Choice Rate and Confusion

Despite California's efforts to encourage beneficiaries to choose a health plan, many beneficiaries have been assigned to a plan by the state. Long-standing problems with California's HCO program, which provides beneficiaries with information about their managed care options and enrolls them in a plan, may have contributed to this and to widespread confusion among beneficiaries. While many agree that the HCO program is running smoother now than in the past, deficiencies persist—some serious enough to have prompted HCFA to delay full implementation in several counties earlier this year.

---

[13] Specifically, the commercial plan was in violation of Medicaid's "75/25" restriction, which provides that a plan's Medicaid (and Medicare, if any) enrollment must be less than 75 percent of its total enrollment. Under its current PHP contract, the commercial plan that serves both San Bernardino and Riverside counties had not complied with the requirement. The Balanced Budget Act of 1997, section 4703, repealed the requirement.

State's Education Process Has Not Resulted in Beneficiary Selection of Plan

To encourage Medi-Cal beneficiaries to choose their own managed care plan, California's HCO program provides them information on managed care and their available health plan options. Plans, advocates, and researchers agree that beneficiaries who are well informed about managed care—and how it differs from fee-for-service—are more likely to choose a health plan, and those who choose a health plan are more likely to stay with that plan. Experts also believe that well-informed beneficiaries are more likely to use health services appropriately, such as relying more on a primary care physician and less on inappropriate use of emergency room services.

Despite its efforts, the state estimated in January 1997 that the majority of enrollments had been the result of automatic assignments by the state. The automatic assignment rate for Alameda County at the beginning of implementation was estimated as high as 80 percent. Although automatic assignment rates have declined—the automatic assignment rate for two-plan counties averaged 45 percent from March to June 1997—the rates ranged widely from county to county. For example, the automatic assignment rate in Contra Costa County in April 1997 was 72 percent, while in Santa Clara County it was 32 percent.[14] Unlike other states, California has not established a numeric goal for automatic assignments. Regardless, California's automatic assignment rates have varied enough across counties to indicate potential problems with HCO's program.

HCFA, advocates, and managed care plans have expressed concerns about the adequacy of the state's efforts to inform beneficiaries about their Medi-Cal managed care options. According to these groups, information in the enrollment packet was complex, lengthy, and written at too high a grade level.[15] In some cases, the information was incorrect. For example, enrollment packets sent to some beneficiaries in San Bernardino and Riverside counties stated that automatic assignments would be made to Molina Medical Centers—a plan not contracted to serve beneficiaries in the expanded program in these counties at that time. Information in the enrollment packets could also be confusing. In anticipation of the Los Angeles County local initiative's beginning operations in April 1997, thousands of beneficiaries in Los Angeles County received packets with cover letters dated January 8, 1997, that instructed them to respond by January 18, 1997—which did not allow beneficiaries the required 30 days

---

[14] DHS believes that the default rate is high because many beneficiaries do not prefer one plan over the other or because they agree with the assignment that the state intends to make.

[15] HCFA first identified problems with the content of the enrollment materials with the implementation of the GMC program in Sacramento in 1994.

to respond. DHS remailed the letters and provided additional time for beneficiaries to respond. And it has only been recently—more than a year after full implementation of the mandatory program in the first county—that many of the enrollment materials have begun to be translated into all of the state's "threshold" languages.[16] Although DHS has established a work group to address problems associated with the enrollment packet, all planned changes are not expected until November 1997, at which time many beneficiaries will have already been enrolled.[17]

Initially, there also were a number of problems with the toll-free call center, which was set up to provide beneficiaries access to additional information about how health plans operate and how to use them. The call center, however, often was a source of frustration and confusion because callers could not get through, messages went unanswered, voicemail boxes were full, or counselors provided incorrect information. However, a review of HCO's recently instituted "problem log" revealed that the problems have largely disappeared under the current enrollment broker, Maximus, which expanded the call-center operation.

There also have been problems with the HCO presentations. Through county-by-county preimplementation reviews, HCFA often found that the presentations were confusing, not conducted in the appropriate language, not accurate or performed as scripted or scheduled, or not sufficiently informative. In addition, beneficiary attendance has been low. State officials recognize that the limited number of presentation sites may make it difficult for beneficiaries to attend. For example, in June 1997, Los Angeles County—which comprises 88 cities and 136 unincorporated areas and covers over 4,000 square miles—had 35 presentation sites.

Officials from one managed care plan we contacted believed that poor attendance at the HCO presentations was due in part to limitations in the state's outreach to beneficiaries. The officials believed that by working closely with community-based organizations that beneficiaries know and trust, such as churches and legal aid services, more beneficiaries could be reached; in addition, these organizations could provide outreach services

---

[16] The state requires the enrollment broker to provide linguistically appropriate services to a population group of mandatory Medi-Cal eligibles residing in a proposed service area whose primary language is not English if these eligibles meet a specific numeric "threshold" in a proposed service area. For example, in Alameda County, the first county in which the program was implemented, the number of eligibles whose primary language was not English exceeded the threshold for Spanish, Cantonese, Vietnamese, and Farsi. The state's threshold languages are Cambodian, Cantonese, Farsi, Hmong, Lao, Russian, Spanish, Vietnamese, and Armenian.

[17] A number of changes have already been completed, such as translation of some of the enrollment materials, including the enrollment exemption form and the list of important telephone numbers.

and thereby supplement HCO presentations. HCFA, advocates, and managed care plans have long called for increased outreach efforts—not only to beneficiaries, who can be difficult to reach, but to providers and others in the community as well. Some plans and advocates have, at their own expense, conducted outreach activities to fill the perceived gap in the state's efforts.

Yet even with high automatic assignment rates and poor attendance at the HCO presentations, it was not until October 1996 that DHS began development of an outreach campaign that was implemented in selected counties in March 1997. The campaign consisted of bus billboards and posters sent to HCO presentation sites, managed care plans, and community-based organizations. Brochures, a video, and radio announcements were also recently added.

DHS has recently begun to explore additional ways to improve outreach and involve community-based organizations in HCO activities, such as participating in DHS-sponsored work groups. DHS asked community-based organizations to identify additional HCO presentation sites in Los Angeles County and plans to require Maximus to contract with a number of community-based organizations to provide HCO presentations to their clients. Recognizing that provider education could also be improved, DHS has begun to better disseminate information to participating providers on managed care programs, such as DHS provider bulletins that give HCO program updates. In addition, DHS created the HCO Education and Outreach Unit in June 1997 to develop and implement strategies to ensure beneficiaries, providers, legislators, advocates, and other interested parties are well informed and educated about the expansion program.

Enrollment Processing Improved, but Problems Still Persist

Some of the problems with enrolling beneficiaries persisted throughout the state's first year of implementation of its new mandatory program and were exacerbated by the timing of the changeover between enrollment brokers. While many agree that enrollment processing is functioning much smoother now, there was enough lingering concern to have prompted HCFA to slow the pace of enrollment in several counties earlier this year.

During the first year of implementation, the volume of enrollments may have overwhelmed Benova, the former enrollment broker. Enrollment materials were not always sent on time, and, in one county, it could not be determined whether they were sent at all. Enrollment data were not accurately or completely entered into the enrollment information system, and some beneficiaries were enrolled in a plan other than the one they chose or were assigned to a plan that was not an option for them. State assignments of beneficiaries who did not choose a plan were not always timely, which meant that plans lost capitation revenue. The situation worsened when Benova lost its bid for the enrollment broker contract and began losing significant numbers of staff.

HCFA and managed care plans agree that Medi-Cal's enrollment process has begun to function more smoothly. Maximus has more resources to process and track enrollments, and the state has begun to implement long-needed fixes, such as improved monitoring of the enrollment broker. However, problems have continued to occur. For example, in April 1997, thousands of beneficiaries in Riverside County were sent letters with dates that implied beneficiaries had already been assigned to a plan. The state remailed the letters with corrected dates.

Because of continuing concerns, HCFA slowed enrollment in several counties earlier this year. According to HCFA, it would not approve the February 1997 full implementation in Santa Clara and San Joaquin counties because it had found, during its preimplementation reviews, deficiencies in the education process that "grossly violated" the HCO process and the conditions of California's waiver. For example, enrollment packets sent to beneficiaries were incomplete, and the state could not verify whether a subsequent mailing was sent.

At the end of March 1997, HCFA decided to slow enrollment in Los Angeles County, prior to full implementation. HCFA took this action, in part, because the enrollment broker had not yet demonstrated an ability to send timely or accurate mailings to beneficiaries or to properly train HCO counselors to make accurate and informative presentations to beneficiaries. Adequately educating beneficiaries in Los Angeles about their plan options is especially difficult, since there are multiple plans from which beneficiaries can choose. Furthermore, with over 1 million beneficiaries who will be mandatorily enrolled, and another 400,000 voluntarily eligible, the consequences of enrollment errors in Los Angeles County could be significant.

Potential Impact of Education and Enrollment Problems on Beneficiaries and Plans

Based on anecdotal evidence from HCFA, advocates, and managed care plans, the problems with the education and enrollment processes throughout the implementation of the two-plan model have affected beneficiaries and plans alike. Officials from one plan said that beneficiaries were not only confused but concerned because they did not understand what was happening to their health care coverage—some beneficiaries thought they were losing Medi-Cal benefits altogether. According to some plans, enrollment problems have resulted in significant financial loss due to lost capitation revenue and unanticipated operating and administrative costs. For example, if enrollment was delayed, some plans not only lost revenue but may have unnecessarily expended funds for staffing, facilities, and advertising. Officials at one local initiative claimed gross revenue losses of almost $2 million due to a 25-day delay in the mailing of enrollment materials. The lost capitation revenue required the plan to draw upon an existing line of credit—with interest—from the county.

Because of long-standing problems and concerns over the implementation of the two-plan model, some groups wanted implementation either stopped or further delayed. Yet, some plans urged the state and HCFA not to delay implementation and enrollment further because of the financial repercussions. HCFA officials agreed that long delays in implementation could present financial hardship for some plans.

Weaknesses in State Management of the HCO Program Contributed to Implementation Difficulties

Over the past several years, California has been criticized for a number of weaknesses in the management of its Medi-Cal managed care program. In a 1993 report, HCFA questioned whether DHS, with its existing staffing and processes, could effectively monitor the state's contracts with Medi-Cal managed care plans.[18] Two years later, we echoed similar concerns. In 1994, HCFA also cited a number of weaknesses in the implementation of Sacramento's GMC program, including the need for early and ongoing local input into the planning process and deficiencies in the education and enrollment process.[19] More recently, Mathematica Policy Research, Inc., in its 1996 report on Medi-Cal managed care, cited limited time and resources

---

[18] HCFA region IX, "Review of California's Administration of Its Managed Care Program" (internal document, fiscal year 1993).

[19] According to HCFA, there were a number of lessons learned from the GMC implementation experience, including the critical need for a well-informed provider and beneficiary population and the importance of an effective monitoring system, such as key performance indicators like disenrollment rates.

as the cause of initial enrollment problems experienced by beneficiaries in Sacramento's GMC program.[20]

These and other management weaknesses—such as insufficient contract performance requirements for enrollment brokers, inadequate monitoring of the HCO program, and poor communication with and involvement of outside groups—contributed to the problems the state encountered in implementing its two-plan model.[21] Benova and Maximus also cited reasons that made it difficult for them to perform as efficiently as possible. The state has taken a number of long-needed actions aimed at improving various aspects of the HCO program. However, the effect of some of these actions remains to be seen.

Federal guidance on designing and implementing a mandatory managed care program, especially when education and enrollment functions are contracted to an enrollment broker, may have assisted the state in improving its program implementation in its earlier stages. Although HCFA is currently developing such guidance, HCFA's oversight of California's program has consisted primarily of approving the waiver application and conducting preimplementation reviews of each county prior to full implementation.[22]

Contracts Insufficient to Hold Enrollment Brokers Accountable

DHS' contract with Benova, the former enrollment broker, contained no specific performance standards. Performance standards should make clear the level of service expected of the broker and enable a state to gauge the sufficiency of the broker's operations. When tied to payment, performance

---

[20] Specifically, the Mathematica report said the initial enrollment process was "chaotic," partially due to enrollment materials that were incomplete, confusing, and sometimes misleading and a call center that was overwhelmed with the volume of calls. Because of the magnitude and frequency of problems, the state provided beneficiaries additional time in which to choose. Mathematica Policy Research, Inc., Managed Care and Low-Income Populations: A Case Study of Managed Care in California (Washington, D.C.: Mathematica Policy Research, Inc., May 1996).

[21] According to DHS, understaffing has also plagued the program. For fiscal year 1996, the Medi-Cal Managed Care Division requested an additional 126 staff to operate its managed care program. However, the state legislature approved somewhat less than two-thirds of these positions. The Payment Systems Division is currently seeking an additional 26 staff positions for the HCO program. Officials say that they need to request more staffing but have been unable to devote the resources needed to prepare the justification.

[22] HCFA's approval of California's waiver was contingent upon several factors, including agreement that full implementation of the two-plan model would not commence in a county until HCFA had conducted a satisfactory on-site, preimplementation review that focused on policies and procedures regarding enrollment, beneficiary access, quality of care, and plans' financial solvency. The waiver also included a requirement that the state demonstrate that it had allocated sufficient and appropriate staff to all areas of responsibility, particularly with regard to setting up and monitoring such a large and complex program.

standards can provide incentives for the enrollment broker to provide the services required and penalties for nonperformance.

DHS' contract with Maximus, the current enrollment broker, contained several performance standards; however, few were tied to payment. For example, although call-center staff were required to answer phones within three rings and process enrollment forms within 2 days, there was no penalty for noncompliance. More importantly, no performance standards that were tied to payment related to potential quality indicators, such as the rate of automatic assignment, beneficiary satisfaction with the education and enrollment process, or the rate of beneficiary disenrollment.[23] California is planning to amend Maximus' contract to include additional performance standards and to increase the number of standards that are tied to payment, which should help strengthen the contract and make it more enforceable.

HCO Program Poorly Monitored

According to HCFA, many of the problems with the state's process for educating and enrolling beneficiaries were the result of inadequate monitoring of the HCO program. Until recently, DHS did not conduct on-site monitoring of enrollment broker activities nor did it have staff with the expertise to monitor the broker's automated systems. In addition, HCO's management information and reports were not adequate to effectively monitor the program.

According to DHS, regular, on-site monitoring of Benova was difficult since Benova's operations were about 80 miles from DHS headquarters in Sacramento. Without on-site monitoring, however, DHS could not guarantee that critical broker responsibilities, such as the mailing of enrollment packets, were carried out. For example, it was not until enrollment broker operations were transitioning to Maximus that DHS found that thousands of beneficiary enrollment packets had not been sent from a Benova mail facility. To help ensure this does not recur, as a condition of its contract, Maximus operations are located in or near Sacramento. DHS also has dedicated five full-time Payment Systems Division staff, four of whom have automated systems expertise, to conduct on-site monitoring at Maximus' various locations. To help ensure Maximus complies with the terms of its contract, DHS staff observe the broker's operations and test the automated systems. Staff also observe mail facility

---

[23] DHS does not believe that it would be fair to tie performance standards on these indicators to payment because the enrollment broker contract does not provide the broker with much flexibility in how to conduct the HCO program.

operations to ensure the timeliness, completeness, and accuracy of the enrollment materials mailed to beneficiaries.

Until recently, HCO program staff did not have the expertise to evaluate automated systems operations and ensure that their outputs were valid. Without such expertise, the state could not determine if beneficiaries had been assigned to plans as intended. Moving day-to-day HCO program operations from the Medi-Cal Managed Care Division to the Payment Systems Division provided the program with the expertise required to make such determinations. In addition, in March 1997, DHS contracted with a systems consultant, Logicon, to test Maximus' automated systems and validate its output by July 1997. According to a DHS official, the testing and validation process will allow DHS to better understand the enrollment broker's system and thus have greater confidence in its output. Validating system output will likely enhance the reliability of the information that the system generates, such as enrollment and disenrollment data. As of the end of August 1997, however, Logicon had yet to complete its contract. As a result, according to HCFA, there remains no external verification that the enrollment broker can effectively handle the increased volumes of enrollment that will result when plans in the remaining counties, like Los Angeles, become fully implemented.

Management information and reporting also were not sufficient to effectively monitor the HCO program. According to one DHS official, HCO reports were not managerially useful. For example, while data were provided on the number of beneficiaries who chose a plan, the number who were automatically assigned to a plan,[24] and the number who disenrolled from a plan, the reports did not include trend analyses. And while an automatic assignment rate was calculated, a disenrollment rate was not, which can serve as an important indicator of beneficiary satisfaction with plans.[25] In addition, certain key terms, such as "disenrollment," have yet to be defined, and the data have yet to be verified, which provides little confidence in its meaning or accuracy.[26] As part of its contract, Logicon is required to ensure that numbers across

---

[24] Prior to January 1997, DHS did not publish data on automatic assignments.

[25] While DHS requires plans to conduct annual enrollee satisfaction surveys, there is no requirement to distinguish between beneficiaries who chose the plan and those who were automatically assigned.

[26] For example, disenrollment can be involuntary due to loss of Medicaid eligibility. Voluntary disenrollments can be due to moving outside the plan service area or dissatisfaction with the plan or provider services. Analyzing reasons for disenrollment can provide valuable information about a plan's performance.

reports are consistent and reconcilable and to identify reports that are needed for the state to effectively monitor enrollment broker activities.

Finally, DHS initially had no system to determine whether problems reported to DHS were recorded or addressed. Although DHS began keeping an HCO "problem log" in January 1997 to capture and track the status of problems and complaints reported to either DHS, the enrollment broker, or the Medi-Cal managed care ombudsman,[27] DHS had not summarized or systematically analyzed the information collected at the time of our review.

Insufficient Communication and Involvement of Outside Groups

HCFA, managed care plans, and advocates have long expressed concern over a lack of effective state internal communication and timely communication with and involvement of outside groups in planning and decision-making. We found, for example, that until recently, HCO policy decisions often were not officially documented or disseminated to the appropriate state staff. DHS has taken some steps to improve its internal communications, such as requiring HCO's policy unit to provide written documentation of all HCO policy decisions to the chief of the Headquarters Management Branch, Payment Systems Division, for review and systematic dissemination.

DHS has also increased its communication efforts with outside groups. To provide a forum to discuss and address issues and concerns, the state has convened or participates in several work groups. For example, the Policy Workgroup was formed in January 1997 to improve the education and enrollment process, such as by redesigning and translating the enrollment materials. The group includes representatives from DHS, HCFA, health plans, advocacy groups, and Maximus. The state also convened in June 1997 a Stakeholder Advisory Group to provide policy advice on and oversight of program implementation in Los Angeles County. The group is composed of advocates, provider representatives, DHS, Maximus, and the Los Angeles commercial plan and local initiative. It plans to meet monthly.

---

[27] The Office of the Ombudsman began operating July 1996. Its purpose, in part, is to investigate and resolve complaints about Medi-Cal managed care and to provide information to and assist Medi-Cal beneficiaries by mediating on their behalf and verifying the resolution of complaints.

Enrollment Brokers Cite Operating Conditions That Affected Their Performance

Benova and Maximus, the two enrollment brokers DHS has contracted with, also cited a number of factors that they believed adversely affected their performance. According to these brokers, DHS made frequent policy and program changes and often provided little lead time to appropriately implement these changes. According to Maximus, during the first 7 weeks of its contract period—which began January 1997—DHS made about 300 policy changes, sometimes giving Maximus little time to implement them. To comply with DHS' time frames, Maximus believed it necessary to sometimes bypass quality assurance measures that it had established to ensure that such system changes did not have unintended consequences. In one instance, changes made to the mailing dates in one county caused Maximus to inadvertently halt mailings to another county.

Benova believed that its performance as Medi-Cal's enrollment broker suffered because of DHS' often-changing directions and its lack of responsiveness. For example, DHS denied Benova's request to transfer calls during peak times to call centers in other states—an arrangement Benova believed would have improved service. According to Benova, DHS also denied its request for cost-reimbursement for additional equipment needed to handle increasing volumes of enrollment.

Benova and Maximus officials also stated that, relative to their experience with other states, California limited their contact with plans, advocacy groups, and community-based organizations. DHS was concerned about remaining informed about program operations and not burdening limited contractor staff with additional responsibilities. DHS recently has relaxed its policy and begun to allow the enrollment broker to participate in community meetings.

Limited Federal Guidance on Education and Enrollment Functions

HCFA's oversight of California's education and enrollment functions has consisted primarily of reviewing and approving the state's waiver application to implement its mandatory managed care program and conducting preimplementation reviews in each county. As of August 1997, few federal guidelines existed for states to use for their process of educating Medicaid beneficiaries and enrolling them in mandatory managed care programs—two relatively new functions for states.[28] In addition, guidelines did not exist for contracting out these functions. With

---

[28] HCFA has issued guidelines to assist states in developing Medicaid managed care marketing standards, which could be applied broadly to the education process. Specifically, federal regulations require that states' contracts with health plans specify the methods by which the plans will ensure that marketing plans, procedures, and materials are accurate and do not mislead, confuse, or defraud beneficiaries or the state.

such guidance, some of the problems that California experienced in expanding its Medi-Cal managed care program might have been avoided.

HCFA is in the process of developing guidelines to assist states with designing and implementing an effective education and enrollment program, including contracting with enrollment brokers—an increasing trend. Earliest issuance of these guidelines was projected for October 1997.[29]

Some Safety-Net Providers Are Encountering Difficulties

An expressed objective of the two-plan model was to protect existing health care safety nets in the new competitive environment of managed care. Safety-net providers—such as federally qualified health centers, and community and rural health centers—provide health care services to the medically indigent. However, while the two-plan model provides some assurances that plans will assign beneficiaries to safety-net providers, it does not guarantee that these providers will receive a specified level of enrollment, nor can it guarantee that they will maintain their enrollments. Some providers have reported that they are having difficulty operating under the two-plan model, especially in maintaining their former patient base.

The two-plan model has several provisions and incentives aimed at protecting safety-net providers. The model's local initiative arrangement enables counties to develop a plan that reflects local needs and priorities and includes county-operated health facilities. Once developed, the local initiative must contract with any safety-net provider that complies with the local initiative's specific requirements and standards and accepts the rates offered. Although commercial plans are not required to contract with safety-net providers, they were awarded extra points during the evaluation process for the extent to which their networks included safety-net providers. The model also requires that automatic assignments be made to the local initiative until preestablished minimum enrollment levels are reached. In addition, the local initiatives and commercial plans are required to ensure—to the maximum extent possible—that existing patient-physician relationships are maintained. Furthermore, the local initiative must develop a process that "equitably assigns" to safety-net providers those beneficiaries who do not choose a primary care provider; similarly, the commercial plan must develop a process that

---

[29] HCFA developed the guidelines with input from selected states; an expert researcher; a review of reports from the National Academy for State Health Policy and GAO; review of states' requests for proposals and contracts; and information from advocacy groups, trade organizations, and the managed care industry.

"proportionately" assigns such beneficiaries.[30] According to DHS, it did not require plans to assign a specific number of beneficiaries to safety-net providers because federal law requires states to ensure that beneficiaries have a choice of providers.

Despite these protections, an initial assessment of the two-plan model's impact on safety-net providers suggests that some are experiencing difficulties, especially in maintaining their levels of enrollment. According to the state and HCFA, a couple of factors have affected safety-net providers' enrollment bases. Beneficiaries in managed care are required to designate only one provider as their primary care physician, although they may have visited more than one provider in fee-for-service care. Consequently, some safety-net providers say that they have seen fewer beneficiaries under the two-plan model. However, many beneficiaries who choose a provider are not choosing safety-net providers, and many who are assigned to these providers disenroll. HCFA has reported that in Los Angeles County, 12,600 beneficiaries—or 70 percent—who had been assigned to a safety-net provider chose to disenroll within 5 days.

The two-plan model does not prescribe, other than in general terms, how plans are to assign beneficiaries to individual providers. However, a number of plans favor safety-net providers in their assignment methodology. One plan had designed a four-tier assignment methodology that gives priority to contracted safety-net providers and other providers that have at least a 50-percent Medi-Cal enrollment base. Another plan seeks to maintain a 60/40 assignment ratio, with approximately 60 percent of beneficiaries assigned to private providers and the remaining 40 percent assigned to county and community clinics.[31]

State Assessing Safety-Net Issue and Taking Some Steps to Assist Providers

The state has begun to assess measures that could be taken to assist safety-net providers and has taken action in one county. To reduce the number of beneficiaries assigned by plans away from their safety-net providers, the state planned to provide information on beneficiaries' last provider of record to plans beginning August 1997. With this information, plans could assign the beneficiary to that provider if the provider was part of the plan's network.

---

[30] "Proportionately" means that the number of enrollees assigned should approximate the proportion that the providers represent in the network. For example, if the safety-net providers represent 20 percent of a plan's network, they should receive approximately 20 percent of beneficiaries.

[31] According to a plan representative, the actual assignment ratio is closer to 70/30, since an average of 80 percent choose their provider, leaving few beneficiaries for the plan to assign—only 1,600 over the last 5 months.

Safety-net providers in Fresno County were particularly concerned about their viability since the county's two-plan model did not include a local initiative. An agreement was reached between the state, providers, and the two commercial plans that addressed some of the short- and long-term concerns of these safety-net providers. For example, the two plans agreed to assign all state-assigned beneficiaries who had not designated a primary care physician to a safety-net provider. Over the longer term, a special team composed of state, plan, and provider representatives will be established to oversee the implementation of managed care in Fresno County.

Conclusions

California's expansion of its Medi-Cal managed care program is currently the largest effort of its kind in the nation in terms of the number of beneficiaries involved. Although California invested nearly 5 years in both conceptual and implementation planning of its two-plan mandatory program, implementation has not been smooth. Many of the circumstances that contributed to implementation problems were within the state's control, while others were not. For example, the timing of the transition from one enrollment broker to another undoubtedly contributed to the implementation delays and difficulties. Had the transition not occurred in the midst of the two-plan implementation in several counties, some problems might have been less severe.

Many of the problems that occurred in implementing the new mandatory program were foreshadowed by the state's earlier efforts to implement managed care. These earlier problems—documented in prior evaluations by other organizations—should have convinced the state that many of its policies and procedures needed retooling. The state is now taking certain actions to improve the program, but many are too late to benefit those beneficiaries already enrolled in the seven counties where implementation has been completed.

HCFA's preimplementation reviews enabled HCFA to identify problem areas in California's implementation of its two-plan model; the reviews did not, however, always result in immediate improvements. At the same time that DHS was attempting to address these problems, managed care plans were exerting pressure to push ahead with program implementation since their large investments—and financial viability—were dependent on receiving enrollments and associated revenues according to set time frames. As a result, while HCFA identified the need for significant improvements, it did not halt program implementation to effect such changes. HCFA also did not have sufficient written guidance in place to assist the state in developing and implementing its program.

Despite these delays and difficulties, California's experience can be instructive for other states as they develop, expand, or adapt their mandatory Medicaid managed care programs. Specifically, California's experience points to several potential lessons learned:

- Incremental implementation allows for adjustments and improvement. Simultaneous or quick-succession implementation in multiple areas does not give sufficient time for program modifications when unforeseen problems arise.
- Sufficient staff—including individuals who have expertise in managed care program design and implementation—are needed to conduct program activities. Of particular importance are systems analysts and contract specialists.
- Stakeholder and community input and involvement, sought early and often, can contribute significantly to effective education and enrollment processes and problem resolution.
- Effective monitoring systems, including adequate management information and reporting, can ensure accountability for program operations—especially if there is heavy reliance on a contractor for integral parts of the program. Including performance standards for key areas of operation in enrollment broker contracts and tying these standards directly to broker payment might help to ensure maximum contractor performance.

Recommendation

To help states design and implement Medicaid managed care programs that ensure beneficiaries who enroll—especially those who are mandated to do so—are able to make an informed choice in selecting a plan, we recommend that the Secretary of Health and Human Services direct HCFA to promptly finalize guidelines for developing and operating an education and enrollment program. To help ensure accountability, these guidelines should include considerations regarding appropriate performance standards and measures and monitoring mechanisms, especially when a state contracts out these functions to an enrollment broker.

Agency Comments and Our Evaluation

We provided a draft of this report to the Administrator, HCFA; Director, California DHS; and officials of Benova and Maximus, the former and current enrollment brokers. Each entity provided technical or clarifying comments, which we incorporated as appropriate.

HCFA concurred with our recommendation and stated it is working to finalize its education and enrollment guidelines. For example, it sponsored a joint industry and Medicaid managed care meeting in September to discuss the draft guidelines. HCFA did not, however, indicate a target date for finalizing the guidelines. HCFA's Administrator stated that, because the guidelines are not requirements, it is important to take the necessary time to reach consensus on them in order to obtain necessary buy-in and endorsement from those affected in order to give the guidelines credibility and acceptability.

DHS agreed with our conclusions and recommendation, saying that the state has already adopted or is working toward implementing the lessons learned that were outlined in the conclusions. It acknowledged that there have been problems associated with California's transition to managed care for its Medi-Cal population and emphasized its efforts to address these problems in partnership with HCFA, plan partners, medical providers, and advocacy groups; however, the state was concerned that the report did not sufficiently acknowledge its efforts in this regard. DHS provided to us additional information on its efforts to be responsive to identified problems, which we incorporated where appropriate. In terms of the evidence and findings presented in the report, DHS questioned the objectivity of information obtained from some sources, such as some contracted health plans and the former enrollment broker, with whom the state is involved in formal contract disputes or litigation. Being aware of these ongoing disputes and litigation during the course of our work, we were sensitive to the use of information obtained from all affected parties. In this regard, we either corroborated the testimonial evidence we obtained with independent sources or clearly attributed the information to its source in the report.

Both Benova and Maximus generally concurred with our findings. Benova provided additional information on several findings in order to more fully explain its relationship with the state and the resulting impact on Benova's performance. For example, Benova contends that its contract was not adequately funded to fulfill the enrollment contract functions. We chose, however, not to include these additional details because of ongoing litigation between the two parties. Maximus generally agreed with our assessment of the program and implementation issues. Despite the difficulties cited in the report, Maximus believed that it has gained sound administrative control of the basic enrollment processes, such as the call center operations, the enrollment process, and the computer system operations. While Maximus endorsed holding all program participants accountable, it emphasized that establishing standards for functions that are not entirely within its control can be problematic—especially when these functions are tied to payment. Maximus added that the California experience has served as an important learning opportunity in its role as enrollment broker in other states.

As arranged with your office, unless you announce its contents earlier, we plan no further distribution of this report until 30 days after its issuance date. At that time, we will send copies to the Secretary of Health and Human Services; the Administrator, HCFA; the Director, California DHS; and interested congressional committees. Copies of this report will also be made available to others upon request.

If you or your staff have any questions about the information in this report, please call me or Kathryn G. Allen, Acting Associate Director, at (202) 512-7114. Other contributors were Aleta Hancock, Carla Brown, and Karen Sloan.

Sincerely yours,

William J Scanlon

William J. Scanlon
Director, Health Financing and
Systems Issues

Contents

Abbreviations

AFDC	Aid to Families With Dependent Children
COHS	County Organized Health System
DHS	Department of Health Services
GMC	Geographic Managed Care
HCFA	Health Care Financing Administration
HCO	Health Care Options
PCCM	Primary Care Case Management
PHP	prepaid health plan
SSI	Supplemental Security Income
TANF	Temporary Assistance for Needy Families

Appendix

Scope and Methodology

To determine the status of California's expansion of its Medi-Cal managed care program and identify potential reasons for delays in implementing the two-plan model, we interviewed officials from the California Department of Health Services (DHS) and reviewed their implementation schedules—the initial schedule and subsequent updates—for the two-plan model. We also interviewed Medicaid officials in HCFA's region IX office in San Francisco and examined their preimplementation reviews, which are conducted in each affected county to determine the state's readiness to implement the two-plan model in that county.

To identify the state's efforts to educate Medi-Cal beneficiaries about managed care and enroll them into one of the state-contracted plans, and to evaluate its management of the education and enrollment process, we interviewed DHS and HCFA region IX officials and obtained and reviewed relevant state law, regulations, policies, and procedures; the state's strategic plan for expanding its Medi-Cal managed care program; the state's two-plan model waiver application submitted to HCFA; Health Care Options (HCO) program documents, including enrollment materials; minutes from DHS' Policy and Transition Workgroup meetings; HCO's problem log; enrollment broker contracts and the 1995 Request for Proposal; HCO management reports, including monthly enrollment summaries; and HCFA's preimplementation reviews. We also interviewed officials from two commercial and four local-initiative health plans that served 11 of the 12 two-plan counties; Benova, Medi-Cal's previous enrollment broker, and Maximus, its current enrollment broker; and advocacy and consumer groups. We reviewed documents obtained from these officials, including minutes from the California Alliance of Local Health Plan Enrollment Workgroup meetings and written testimony of some stakeholders on the implementation of the two-plan model provided in February 1997 before the California state legislature. We also reviewed reports by Mathematica Policy Research, Inc., and the Medi-Cal Community Assistance Project that discussed issues and concerns about DHS' expanded program.

To evaluate the state and federal oversight of California's enrollment broker, we obtained and analyzed California's past and current enrollment brokers' contracts and amendments. To obtain detailed information on specific DHS activities to monitor enrollment broker performance, we interviewed DHS and HCFA region IX officials. We also visited Maximus' administrative office, which houses its systems operations and call center, and one of the subcontracted mail facilities to observe broker operations. At these facilities, we met with DHS and Maximus officials to discuss oversight activities and broker operations. We also reviewed program information generated by Maximus. To identify federal monitoring of contracted enrollment broker functions and guidance for states to use in monitoring contracted enrollment broker activities, we met with officials in HCFA's Baltimore Office of Managed Care and region IX Medicaid officials. In addition to reviewing HCFA's guidelines for state compliance with federal regulations on Medicaid managed care marketing, we obtained and reviewed HCFA's "Managed Care Pre-Implementation Review Guide" and its draft guidelines to states for enrolling beneficiaries in managed care programs.

To make an initial assessment of the two-plan model's impact on safety-net providers, we interviewed officials from DHS, HCFA, and two commercial and two local initiative plans. We also reviewed the state's strategic plan, which discusses how safety-net providers would be included under the two-plan model; state requirements for assigning beneficiaries to plans; and selected plan assignment methodologies. In addition, we reviewed reports by the Medi-Cal Community Assistance Project and Mathematica, which examined the experiences of some safety-net providers.

We performed our work between January and August 1997 in accordance with generally accepted government auditing standards.

Medicaid Managed Care: A Guide for States

3RD EDITION

Volume IV

Challenges and Solutions: Medicaid Managed Care Programs Serving the Elderly and Persons with Disabilities

August
1997

NATIONAL ACADEMY
for STATE HEALTH POLICY

50 Monument Square, Suite 502 Portland, Maine 04101
Phone 207-874-6524 ■ Fax 207-874-6527 ■ email: info@nashp.org

Funded by The Center for Health Care Strategies and The Pew Charitable Trusts
Additional funding for this volume provided by The Henry J. Kaiser Family Foundation and
The Health Care Financing Administration

ACKNOWLEDGEMENTS

This Volume of the **Guide** would not have been possible without the financial support of both The Center for Health Care Strategies and The Pew Charitable Trusts. We would like to thank Stephen Somers, Karen Brodsky and Ruth Martin of The Center for Health Care Strategies and our Pew Project Director, Linda Rich, for the insight and encouragement they provided.

In addition to crucial financial support, this Volume would not be possible without the knowledge and assistance of people working in the field. We wish to thank those state, plan and advocate staff from Arizona, California, New Jersey, Oregon, Tennessee, and Utah who took the time to meet with us during our site visits to gather information for this Volume and to review the draft of the Volume. Special thanks goes to those who arranged our visits. They are: Kim Freeman and Lynn Martinez of Arizona; Alan Stolmack of California; Gretchen Brown and Mary Dewane of CalOPTIMA; Margaret Soltis and Daniel Walsky of New Jersey; Joel Young of Oregon; Theresa Clarke and Keith Johnson of Tennessee; and Edward Furia and Holly Balken of Utah.

There were also additional people who took the time to review drafts of this document to whom we offer our thanks and appreciation. In addition to those mentioned previously, they are: Richard Allen of Colorado, David Parrella of Connecticut, Nancy Hale of HMO Oregon, Fran Finnegan and Chris Zukas-Lessard of Maine, Bruce Bullen and Mary Beth Fiske of Massachusetts, Mary Kennedy and Pam Parker of Minnesota, Maureen Booth of the Muskie School of Public Service and a Fellow with the National Academy for State Health Policy, Barbara DeBuono, Barbara Frankel and Elizabeth MacFarlane of New York, Hersh Crawford of Oregon, Michael Jacobs of Pennsylvania, Tricia Leddy of Rhode Island, Linda Wertz of Texas, Robert E. Hurley of the Commonwealth University of Virginia, Jane Beyer, Julie Lake and Margo Westfal of Washington and Angie Dombrowicki and Peggy Bartels of Wisconsin.

Finally, the production of this Volume would not have been possible without the contributions of the Academy's own: Cynthia Pernice who produced the graphs contained in this Volume and Mary Jo Torgerson who designed the covers.

Medicaid Managed Care: A Guide for States, Third Edition

Volume IV

Challenges and Solutions: Medicaid Managed Care Programs Serving the Elderly and Persons with Disabilities

TABLE OF CONTENTS

Chapter 1
Program Design Issues

Chapter 2
Care Delivery

Chapter 3
Medicaid Managed Care and Mental Health

Chapter One

Program Design Issues

Paul Saucier
Muskie School of Public Service
University of Southern Maine

August
1997

NATIONAL ACADEMY
for STATE HEALTH POLICY

Chapter 1
Program Design Issues

Overview of Medicaid Managed Care for Special Populations

Risk-based Medicaid managed care for older persons and persons with disabilities continues to grow. By January 1997, 25 states plus the District of Columbia were enrolling older people, people with disabilities or both into plans with some degree of provider risk, up from 20 states in May, 1995.[1] In many of these states, actual enrollment is very low, reflecting decisions to proceed slowly with small, voluntary pilot programs, but other states (notably Arizona, Minnesota, Oregon, and Tennessee) have mandatory programs with significant numbers of elderly people or people with disabilities or both enrolled. Many states report plans to expand their efforts in the near future. Twenty-three of the 26 states currently enrolling the elderly or people with disabilities reported impending changes in their programs, with most planning expansion of risk-based care in one manner or another. Forms of planned expansion include: covering a specific population for the first time; expanding an existing program geographically; moving from voluntary to mandatory; including a particular service (such as long term care) in the capitation for the first time; and phasing out primary care case management (PCCM) or partially capitated programs in favor of full risk arrangements.

Despite the growth and evolution of individual programs, the states are not yet converging on key program design decisions. The 26 states are about evenly divided on whether to have mandatory or voluntary programs, and on whether to create specialty programs or include special populations with Transitional Assistance for Needy Families (TANF) beneficiaries. The subpopulations included in programs covers a broad spectrum of conditions, including developmental disability, physical disability and mental illness.[2]

The variety of approaches reflects the diversity of the states themselves, but also points out Medicaid managed care's lack of experience in this area. The body of

---

[1] Joanne Rawlings-Sekunda, *Directory of Risk-Based Medicaid Managed Care Programs Enrolling Elderly Persons or Persons with Disabilities (Update: January 1997)*, (Portland, ME: Center for Vulnerable Populations, 1997).

[2] It is important to note that Title IV-H of the Balanced Budget Act of 1997 will allow states, effective October 1997, to mandate enrollment of all Medicaid beneficiaries into managed care without need of a federal waiver except: dual eligibles (those receiving both Medicaid and Medicare), certain children with special needs, and (in most circumstances) American Indians. States will still need to obtain waivers before mandating enrollment of these three groups into managed care.

independent research is growing, but most of the major work to date has focused on older people generally, and Medicare risk plans in particular. With the exception of the HCFA sponsored evaluation of Arizona's program,[3] states have no major Medicaid managed care studies offering specific guidance on approaches to older people and people with disabilities. This will change shortly, as independent evaluations of other §1115 waiver programs are completed. In particular, the disability module of the Oregon Health Plan evaluation should be of great interest to other states. In the meantime, several studies can provide some insights into the managed care's potential affect on the health care delivered to the elderly and persons with disabilities.

The Medical Outcomes Study[4] found that older people and poor chronically ill people had worse physical health outcomes in HMOs than comparable people treated in fee-for-service settings. Furthermore, this pattern was the opposite of that found for non-poor, non-elderly participants, who fared better in HMOs, suggesting that what works for the average person may not work for special populations. The study included a variety of HMO settings in Boston, Chicago and Los Angeles.

In a study of 450 frail older people in San Diego, Experton et al.[5] identified a troubling utilization pattern for those in Medicare HMOs. Compared to fee-for-service study participants, those in Medicare HMOs received 71% fewer home health visits. While this finding alone does not suggest worse care, the study also found that the Medicare HMO members were over four times as likely to have any hospital readmission, and over seven times as likely to have a preventable hospital readmission. The authors conclude that, while managed care may encourage more judicious use of services for younger, healthy populations, application of the same utilization approaches may limit beneficial care for frail older people. It should be noted that the Medicare HMOs in the study were not responsible for long term care, perhaps lending support to the argument that capitation of acute care without regard to long term care provides perverse incentives to reduce acute costs, since long term care consequences are not borne by the HMOs.

---

[3] Nelda McCall et al., *Evaluation of Arizona's Health Care Cost Containment System Demonstration (Final Report)*, (San Francisco: Laguna Research Associates, 1996).

[4] John E. Ware et al.,1996. "Differences in 4-Year Health Outcomes for Elderly and Poor, Chronically Ill Patients Treated in HMO and Fee-for-Service Systems." *Journal of the American Medical Association* 276 no. 13 (1996): pp.1039-1047.

[5] Bettina Experton, et al., "The Impact of Payor/Provider Type on Health Care Use and Expenditures among the Frail Elderly," *American Journal of Public Health* 87 no. 2 (1997): pp. 210-216.

Other studies attest to improved access and equivalent or better outcomes for older people in managed care. A 1994 article reviewed 16 studies comparing the quality of care provided by HMOs to care provided to similar populations by other delivery systems. The article found HMO quality of care to be equal to or better than care provided by other delivery systems in 14 of 17 indicators.[6] Another study concluded that Medicare HMO enrollees are more likely to receive mammograms than those on fee-for-service (62% versus 39%). This study also found that low income and African American HMO enrollees were even more likely than the average HMO enrollee to receive a mammogram.[7] Finally, another study found no differences in access, satisfaction, and quality of care among Medicaid beneficiaries enrolled HMOs and those in fee-for-service. This study found that HMO enrollees had lower utilization but were equally as healthy as fee-for-service beneficiaries. (Health outcomes measured included: general health status, physical functioning, activities of daily living, visual acuity, blood pressure and diabetic control).[8]

Although not directly applicable to many state-based efforts these studies demonstrate that managed care can have both positive and negative impacts on the care delivered to members of special populations. Also, the Ware and Experton studies offer an important caution to states undertaking managed care with special populations: traditional HMO approaches proven to work with average people may have different results with special populations. As states expand into this area, they should be deliberate in their strategies, build in strong quality oversight mechanisms, and remain flexible enough to make midcourse corrections as needed.

What Are the Program's Goals?

Given the untested nature of risk-based managed care for persons with disabilities and the elderly, why would a state want to apply this approach to these special populations? It is important for any state to ask itself this question early on, and to establish goals and objectives that will guide the development and refinement of its managed care initiative.

In every state, older people and people with disabilities account for a disproportionate share of total Medicaid expenditures, stemming from above average use of expensive, institution based care. Community care, when it is available, is often marked by a confusing array of services that may or may not be

---

[6] Robert H. Miller and Harold S. Luft, *Journal of the American Medical Association*, May 1994.

[7] Nelson, et al, Physician Payment Review Commission, November 1996.

[8] Lurie, et al., *Annals of Internal Medicine*, March 1994.

precisely what beneficiaries need. Compared to current fee-for-service arrangements, managed care offers the potential to improve beneficiary outcomes and control expenditures.

Many states are working on programs that would integrate acute and long term care for special populations. It is important to point out that integration itself is not a goal, but an approach that many believe will improve outcomes and control costs.

Improve Consumer Outcomes

Many believe that replacing the fragmented fee-for-service system with a managed, seamless system will result in a user-friendly system with better outcomes. States also report improved access to certain services, particularly primary care and dental services. States believe a good managed care program should:

- emphasize prevention and early intervention services;
- reduce overuse of institutional services in favor of expanded home- and community-based services;
- add flexibility to benefits, allowing care to be highly individualized;
- enhance accountability by holding a single contractor responsible for care over time and place; and
- strengthen coordination of care.

Control Expenditures

States also hope that expenditures can be controlled through the fixed capitation payment method. Budgets continue to grow from year to year in managed care systems, but the growth is a negotiated, predictable increase in rates paid to a contractor, as opposed to unpredictable, open-ended provider reimbursement paid on a fee-for-service basis. Moreover, the capitated payment gives the contractor a strong incentive to manage services closely.

For special populations, states see greater opportunities to substitute less expensive, more desirable home- and community-based care for more expensive institutional care. The evaluators found this to be the case in Arizona's Long Term Care System, where contractors are mostly county-based, but Experton's San Diego study, in which home care was reduced and hospitalization increased for frail older people, is an important reminder that commercial HMOs may not automatically move to increase home- and community-based care in response to a capitated payment.

Will the Program Be Voluntary or Mandatory?

An important and emotional issue states must face is whether to make participation of special populations voluntary or mandatory. States are divided on this question. About half of those enrolling special populations in risk-based programs do so on a mandatory basis. The following table provides examples of voluntary and mandatory programs serving special populations.

Medicaid Choice in Selected State Programs
(Program Status as of May 1997)

Program	Eligible Populations	Medicaid Choice
Arizona	All	Mandatory for all
California County Organized Health Systems (5 counties)	All	Mandatory for all
California Geographic Managed Care (2 counties)	All, though emphasis is on TANF	Mandatory for TANF; Voluntary for all others
Minnesota Prepaid Medical Assistance Plan (PMAP)	Elderly and TANF	Mandatory
Minnesota Senior Health Options (MSHO)	Dually eligible elderly	Voluntary
Nebraska HMO Program	All	Mandatory for all
New Jersey HMO Program	All	Mandatory for TANF in most counties; Voluntary for all others
Oregon Health Plan	All	Mandatory for all
TennCare	All	Mandatory for all
Wisconsin ICare	People with disabilities	Voluntary
Wisconsin Partnership	Elderly and people with disabilities who qualify for long term care	Voluntary

The issue of mandatory or voluntary enrollment is more complicated for older people and people with disabilities than it is for TANF beneficiaries, for a number of reasons.

- Untested Nature. As the introduction to this chapter notes, managed care is still a relatively new concept for special populations, and some early research has given us reason to proceed cautiously. Some believe that voluntary programs are more appropriate for special populations until success is proven.

- Equal Treatment. On the other hand, some states (particularly those with statewide programs) established as a guiding principal that all Medicaid beneficiaries, regardless of eligibility category, would be subject to the same enrollment options. That's not to say that individual exceptions are not made. Oregon, for example, allows people to opt out of managed care when necessary to ensure continuity of care, but exceptions are made on a case-by-case basis, rather than through policy affecting entire groups of beneficiaries.

- Numbers. Risk-based managed care depends on large numbers of members to spread risk. Voluntary programs typically have difficulty attracting members. This has been the case in the Wisconsin Partnership Program, for example, in which enrollment remains low despite concentrated efforts to make the program attractive to potential members. This issue is complicated by the fact that commercial HMOs tend to view older people and people with disabilities as high risk groups, and may be less inclined to participate in voluntary programs, where enrollment (and thus funding) is not guaranteed.

- Waivers. States do *not* need a federal waiver to operate a voluntary program that serves any group of Medicaid beneficiaries or a mandatory program that serves any group of Medicaid beneficiaries *except:* those who are also receiving Medicare, certain children with special needs, and (under most circumstances) American Indians.[9] Since many elderly and persons with disabilities also belong to one of the 'exempted' groups it is likely that states wishing to pursue a mandatory program for the elderly or persons with disabilities will need to seek a waiver. In particular, states interested in including Medicare in a mandatory program for those who are eligible for both Medicare and Medicaid (dually eligible), should be prepared to demonstrate to HCFA that full freedom of Medicare choice (which is unwaivable) is preserved within the program;

- ADA/NRA. The Americans with Disabilities Act and National Rehabilitation Act may impact a state's ability to create mandatory programs for people with disabilities if they are different than the programs serving other populations. As long as managed care is an

---

[9] The ability to mandate enrollment without need of a federal waiver for some groups of Medicaid beneficiaries is effective with contracts entered into or renewed after October 1, 1997. (§4701 and 4710, Title IV-H of the Balanced Budget Act of 1997).

additional option for people with disabilities, it does not result in disparate treatment, but if people with disabilities are required to join a specialty managed care program separate from the program developed for TANF beneficiaries, the state may be subject to legal challenges, even if the state believes the specialty program is more comprehensive or otherwise better than the one serving TANF beneficiaries;

- Constituent Support. Older people and people with disabilities tend to be more effective than TANF beneficiaries in expressing their opposition to state initiatives in legislative and other forums. States may find it easier to gather constituent support for voluntary programs.

Who Will the Program Serve?

At the broadest level, the term "special populations" is generally broken into two distinct groupings: the elderly, who are defined as being 65 years of age or older for Medicaid purposes; and adults with disabilities. Many elderly qualify for Medicaid through Supplemental Security Income (SSI), a needs based program available to anyone 65 years old or older who meets income and asset tests. Although many older SSI beneficiaries have disabilities, they need not be determined disabled to qualify for SSI. Thus, the group of older people with SSI in any given state includes individuals with a broad range of health and social needs, with poverty being their common characteristic. States with medically needy programs extend Medicaid eligibility to older people with income above SSI limits who have significant health care costs. Most older medically needy beneficiaries are nursing home residents, making them a more homogeneous group than SSI beneficiaries.

In order to qualify for SSI, people under 65 must be poor *and* have a disability. Yet the under 65 SSI population is also a diverse group, including three major categories: physical disability, mental illness and developmental disability. Within these disability categories, a wide range of conditions and diagnoses are represented, including AIDS, cardiovascular disease, cancer, cerebral palsy, mental retardation, schizophrenia, paraplegia, multiple sclerosis, stroke and spina bifida.[10]

As a state develops its target group for managed care, the diversity of needs among subgroups of special populations must be considered. The needs of the target group will determine a state's criteria for network adequacy as it chooses managed care contractors. For example, a state that includes all populations in a single managed care program must assess whether all of the disabilities and conditions listed above can be adequately addressed by or through individual managed care networks. By

---

[10] Mari-Lynn Drainoni, Carol Tobias, and Tony Dreyfus, *Medicaid Managed Care for People with Disabilities: Overview of the Population*, (Boston: Medicaid Working Group, 1995).

contrast, a state that excludes people with developmental disabilities from its managed care initiative can pay less attention to network adequacy in mental retardation. The following table identifies various ways to refine target groups.

Target Group Considerations

Criterion	Options
1. Eligibility Status	A. All Groups (SSI, Medically Needy, TANF and Related, including Dually Eligible for Medicare) B. SSI Only C. SSI and Medically Needy Only D. Any of the Above, but Exclude Dually Eligible
2. Age	A. 65 or Older B. Adults with Disabilities Under 65 C. Children with Disabilities D. Combination of Above
3. Long Term Services Need	A. Nursing Facility (NF) Certified Only B. NF Certified and Others not Certified C. NF Certified Excluded
4. Type of disability	A. Physical B. Developmental C. Mental Illness D. Combination of Above E. Subcategory of Above

Eligibility Status

Perhaps the broadest way to think about a target group is to separate special populations into eligibility categories. The options next to Criterion 1 in the table have been oversimplified, but at a gross level, major eligibility categories include TANF and related, SSI and related (which includes both older people and people with disabilities) and Medically Needy. Dual eligibility for Medicare must also be considered, given that 90 to 98% of older Medicaid beneficiaries also have Medicare coverage, as do 30 to 50% of adults with disabilities under age 65. (Percentages of dual eligibility have been found to vary considerably from state to state.)

Several states (including Arizona, parts of California, Oregon and Tennessee) have included all eligibility groups in a single program. Perhaps the most important lesson those states cite is that special populations take longer to enroll, and that other states considering this approach should enroll eligibility groups in stages over a two to three year period.

States including Medically Needy beneficiaries will face particular concerns around rates, given that this group pays a portion of their own cost of care. A major question becomes whether to pay the contractor a uniform rate and have beneficiaries make their spenddown payments to the state, or whether to have the contractor collect spenddown payments and adjust the contractor's rates. Most states have excluded this group from managed care because the eligibility status is largely used to qualify for nursing home services, and to date, only a few states include long term care populations or services in their managed care programs.

Dual eligibility raises several complications (discussed in more detail later in this chapter), and many states have excluded dually eligible people from their managed care programs. Given the significant incidence of dual eligibility, however, excluding dually eligible people places a serious limitation on enrollment.

Age

Another important criterion is age. A few states (Minnesota, Nevada) have created programs that serve older people but not people with disabilities under 65. Others (Delaware, Georgia, Ohio) include younger people with disabilities but not those over 65.

Long Term Care Services Need

States have taken many approaches to people who require long term care (LTC) services. Although LTC includes home- and community-based care, states generally define the need for LTC as meeting a state's criteria for nursing facility certification.

In most states, people in this category are excluded from managed care altogether, since only a few states include extended LTC benefits in their capitated payments to contractors. Some states (such as Oregon) do not include extended LTC in their managed care programs, but still enroll people with LTC needs. In those states, managed care contractors are responsible for primary and acute care needs, and for coordinating their services with LTC providers, who are paid directly by the state on a fee-for-service basis.

Some states have developed programs targeted exclusively to people with long term care needs. These include the Arizona Long Term Care System, pilot projects in California and Florida, the Wisconsin Partnership Program, and several PACE sites (Program of All-inclusive Care for the Elderly) around the country.

Type of Disability

Finally, states must decide whether to target particular disabilities and/or conditions. A number of states (Missouri, Ohio, Wisconsin) have developed programs serving predominately people with physical disabilities. Others (Arizona, New York, Rhode Island) have or are developing programs targeted to people with developmental disabilities. Though several states have mental health "carve-out" programs, none have focused exclusively on people with severe and prolonged mental illness. Rather, they have been constructed as service carve-outs, available to a broad range of people with mental health needs, including TANF beneficiaries.

What Services will the Program Include?

Bearing in mind that older people and people with disabilities have diverse needs, states must consider what services to include in their managed care programs. States can begin by analyzing the utilization patterns of their target groups. Important services are likely to include durable medical equipment (DME), personal care, mental health services and a broad range of long term care, including institutional and community-based. States should also consider unmet needs in their analyses. Perhaps the best example of this is dental services. Most states report difficulty obtaining access to dental services in their fee-for-service programs, particularly for people with disabilities. Arizona and Oregon report that including dental services in a managed care program has been found to improve access significantly (particularly for persons with developmental disabilities); but, the historical fee-for-service claims do not provide an adequate base for predicting utilization in managed care.

What's In and What's Out?

The question for states is not whether a service currently covered will continue to be covered, but rather whether it will be included in a capitated payment to a managed care contractor. If it is not included in the capitation, it will continue to be provided to beneficiaries and paid on a fee-for-service basis. Thus, the question becomes the scope of risk that a state passes onto or shares with the managed care contractor. A state has many options, some of which are portrayed in the following table.

Selected Medicaid Capitation Arrangements

	All-Inclusive Capitation (Option A)	One Capitation Payment Combined with Fee-for-Service (Option B)	Two or More Capitation Payments Combined with Fee-for-Service (Option C)
Primary and Acute	Included in Capitation	Some or all Included in Capitation	Capitation 1
Mental Health	Included in Capitation	Included in Capitation or Fee-for-Service	Capitation 2
Long Term Care	Included in Capitation	Some or all Included in Capitation, or Fee-for-Service	Fee-for-Service
Examples	Arizona Long Term Care System; PACE	New York LTC Pilots; Parts of Oregon Health Plan; Wisconsin Partnership	Parts of Oregon Health Plan; TennCare; Washington

Option A is still quite rare. Pioneered by the Arizona Long Term Care System and PACE (Program of All-inclusive Care for the Elderly), this approach includes all Medicaid funded services in a single capitated payment to the managed care contractor. Minnesota recently moved in this direction with its Senior Health Options program, though contractor liability for nursing facility services has been capped at 6 months in that program, with additional nursing facility payments on a fee-for-service basis when needed. The perceived advantage of this approach is the ability to hold a contractor accountable for total care while closing off avenues for cost shifting from capitated services to those reimbursed on a fee-for-service basis. This may not be possible, however, if the contractor does not have a comprehensive enough network to provide the full range of services or is not willing to be at risk for the full range. Also, a state may not want to use a single contractor for policy, program or political reasons. For example, a state may desire to preserve a direct relationship with community mental health centers or home- and community-based long term care providers.

Most managed care programs for older people or people with disabilities capitate some but not all services, in some variation of Option B. The most common arrangement (e.g., parts of California, Oregon, Pennsylvania) is to capitate primary and acute care and reimburse LTC on a fee-for-service basis beyond short, post-acute stays, but some states are experimenting with other combinations. For example, New York has a set of pilot programs in which LTC is capitated, but primary and acute care are paid fee-for-service. Regardless of which sector a state capitates, it needs to consider the incentives for cost shifting that such systems can create. One way to address this concern is to establish fee-for-service utilization targets and to hold contractors financially responsible when they exceed the targets or reward providers for containing its enrollees utilization of fee-for-service services, an approach that has proven effective in Wisconsin.

Other variations on Option B stem from particular state laws passed with the support of certain provider groups. These include arrangements that exclude pharmacy or dental services from capitation.

Option C appears to be growing in popularity as a number of new states create mental health carve out programs. In those states, mental health services are capitated to a specialty contractor, which may be a national behavioral health firm (as in Massachusetts) or a locally-created entity with roots in the county mental health system (as in parts of Oregon). Primary and acute care are typically capitated to a second contractor, with LTC remaining fee-for-service.

Medicare Services

As previously noted, most older beneficiaries and many younger beneficiaries with disabilities also have Medicare coverage. When Medicare coverage exists, Medicaid becomes the last payor for most primary and acute care services, raising implications for Medicaid capitation rates and coordination of services. These implications are discussed later in this chapter.

How Will Quality Be Ensured?

Given the warnings of early research, how can states ensure high quality in their managed care programs for special populations? Booth[11] has suggested that the design features of most state managed care programs for TANF (formerly AFDC) beneficiaries do not fully address the needs of special populations, but provide a solid foundation for state efforts in this area. States will most likely find that the same techniques used in their quality management systems for TANF beneficiaries (e.g. use of practice guidelines, credentialing, licensing and certification) can also be used to ensure quality of care for the elderly and persons with disabilities, but that the system will need to address new issues that are of particular importance to these new enrollees.

One challenge is the broader range of providers often used by special populations. Commercial managed care organizations are not generally accustomed to having Independent Living Centers, home and community based service providers, or adult foster homes in their networks. Even if these services are not the direct responsibility of the capitated contractor, states should consider monitoring the degree to which all of these distinct provider systems come together to provide seamless care to the beneficiary. Health plans have their own quality initiatives (e.g., NCQA accreditation). Also, many types of providers are already steeped in their own quality initiatives (e.g., the Minimum Data Set (MDS) for nursing facilities and the Outcome and Assessment Information Set (OASIS) for home health) while others have virtually no focused quality improvement programs.

As a starting point, states should consider implementing dynamic processes that can provide early warnings of problems and give voice to beneficiaries. State experience has shown that complaint and grievance systems are most effective when they offer multiple avenues for registering problems, include staff who can communicate effectively with special populations, and are easy to use. Ombudsman or other special positions might be created to address individual and systemic problems that arise around the needs of special populations. (Volume II contains more information on complaints and grievances.)

In the longer term, states will need to define desirable outcomes that are specific to the groups their programs serve, and develop performance indicators to measure success. This is a more difficult undertaking that will evolve as programs gain

---

[11] Maureen Booth, *Look Before You Leap: Assuring the Quality of Care of Managed Care Programs Serving Older Persons and Persons with Disabilities*, (Portland, ME: National Academy for State Health Policy, 1996).

experience with special populations. (Volume II contains more information on the use of outcomes measures.)

With Whom will the State Contract?

Medicaid agencies use a variety of contractors to serve vulnerable populations, including commercial HMOs, county-based plans, community-based providers, and HMO/specialty center partnerships. Selected examples are shown in the table below.

Special Population Contractors: State Examples

Type	Examples
Commercial HMOs	Arizona AHCCCS (CIGNA) Colorado (Rocky Mountain HMO) Oregon (Providence Health Plans) Tennessee (Prudential)
Medicaid Plans, including County Plans	Arizona ALTCS (Maricopa County Health Plan) Oregon (Care Oregon)
Sister State Agency	Arizona ALTCS (Department of Economic Security, for people with developmental disabilities)
Community-based Providers	Massachusetts (Community Medical Alliance) Wisconsin (Partnership)
HMO/Specialty Center Partnerships	Ohio (ABC) Wisconsin (ICare)

A quick glance at the table shows that states are not limiting themselves to one approach. In fact, in order to meet HCFA's two-plan requirement for mandatory programs, states may need to encourage the development of multiple contracting arrangements. Factors states consider when selecting an approach include the following.

Purchasing Philosophy and Market Conditions

A state's purchasing philosophy and the market conditions within the state can affect its contractor selection process in a number of ways.

- Commercial Market. Those states with a well-developed and competitive commercial HMO marketplace may find that these existing HMOs offer the best opportunity to obtain the highest quality health care at the best price. Commercial HMOs already have the infrastructure needed to manage care and so can generally afford to offer the 'best deal'—although some states have also found that what a plan can provide does not always match what a plan is willing to offer. Generally speaking, Massachusetts fall into this category, and Arizona is moving in this direction now that its managed care program (and managed care marketplace) has matured.[12]

- Large Risk Pools. In general, a large portion of the total cost of caring for vulnerable populations is due to the cost of caring for a small number of people within these populations. Some states have found that spreading the risk of subpopulations across the broader Medicaid population better accommodates this situation. The more 'average' costing enrollees a plan has, the less likely it is that a few enrollees with very expensive conditions will cause financial difficulties (with its potential effect on access and quality of care). These states tend to use large, usually commercial, plans instead of small specialty plans.

- Existing Relationships. Most states began their managed care programs with TANF beneficiaries and expanded their programs (or plan to expand them) to special populations. Some states find it practical to build on successful relationships with existing contractors, rather than developing separate relationships for special populations.

- Preserving a Role for Traditional Providers. Many states wish to preserve a role for traditional providers generally, and this issue becomes more significant when special populations are involved. Community-based long term care providers, developmental disability services providers, and county mental health systems may all be valued as critical to the success of any managed care program.

Target Group and Services Purchased

The type of contractor desired will also depend on the target population and services included in the program. A state will want any potential contractor to demonstrate experience working with the target group and network adequacy in all services included in the capitation. If a state is including long term care in its program, commercial HMOs may not be able to show network adequacy, especially in terms of home- and community-based LTC services. Subpopulations may need very specialized services currently available only through traditional providers. States constructing risk-based programs may want to consider combining the insurance expertise of an HMO with the service expertise of a specialty provider.

Availability

Even if the state is willing to do business with certain contractors, those contractors may not be interested in taking on the perceived risk of special populations,

---

[12] It is interesting to note that in at least one state (Minnesota) the managed care marketplace has become so consolidated that this State is considering moving away from purchasing from commercial HMOs and instead purchasing from county-based or network models.

particularly on a full risk basis. Thus, the state may have to stimulate the development of specialty contractors through technical assistance and special payment systems. Many states do not have well-developed commercial managed care markets, particularly in rural areas. They too may need to build systems from the ground up.

Legal Authority

Federal and state laws also influence contractor selection.

- Title IV-H of HR 2015 (PL 105-33) changed several federal regulations to make it easier for states to contract with managed care entities that are not federally-qualified HMOs. For example, this law removes the federal requirement for a Medicaid contracted plan to have at least 25% commercial enrollment and enables states to lock-in enrollees of managed care entities that are not federally-qualified HMOs.

- Medicare Capitation. If a state wishes to include Medicare services on a capitated basis and does not want to go through the waiver approval process, it may need to consider entities with existing legal authority to receive capitated Medicare payments, such as Medicare HMOs, Social HMOs and PACE sites.

- State Insurance Laws. Risk arrangements are subject to state insurance laws, which favor large, financially sound commercial entities. Several states, including Arizona, Connecticut, Oregon and Wisconsin, have obtained exceptions to state insurance laws for at least some of their Medicaid managed care initiatives.

How Will the Program Address Medicare Services?

Medicare can not be ignored as an inconsequential issue among special populations. As previously noted, 90-98% of older Medicaid beneficiaries also have Medicare coverage, as do 30-50% of adults with disabilities under age 65. As first payor for primary and acute care, Medicare coverage carries great cost and coordination of care implications for dually eligible people in Medicaid managed care.

Until recently, states with Medicaid managed care programs took one of two courses toward dually eligible persons. Either they 1) excluded them from the programs or 2) made an adjustment in their Medicaid capitation rates to reflect Medicare eligibility and took no further actions regarding Medicare. More recently, states have pursued a far more active role in ensuring that Medicaid and Medicare work well together for the maximum benefit of dually eligible persons. Approaches fall into two broad categories: those that attempt to coordinate the distinct Medicare and

Medicaid systems, and those that attempt to fully integrate them by building one new program from the two.

Two Basic Approaches to Dual Eligible Beneficiaries

Approach	Distinguishing Feature
Coordination	Emphasis on making two service systems appear and feel as one to the consumer. **Examples** • Medicare and Medicaid enrollment remain separate, but contractor, state and HCFA develop coordinated enrollment process to approximate simultaneous entry into two systems (Oregon). • HCFA and state agree to share the Medicare and Medicaid data collected respectively by the two systems. • HCFA and state maintain separate contracts for Medicare and Medicaid payments, respectively, but payments are made to the same contractor (PACE and Oregon).
Integration	Emphasis on unifying two service systems into one. **Examples** • HCFA authorizes the state to enroll dually eligible persons into a single service system that includes both Medicare and Medicaid (Minnesota). • The state collects (and shares with HCFA) Medicare and Medicaid data (Colorado). • A single contract covers both Medicare and Medicaid services (Minnesota).

Perhaps the most mature example of a coordination approach is Oregon's, in which the state, HCFA and contractors have gone to great lengths to make the Oregon Health Plan (through which most Medicaid beneficiaries are enrolled in managed care) work well with the substantial Medicare HMO market that exists in that State. In most cases, dually eligible beneficiaries who elect a Medicare HMO have their Oregon Health Plan benefits delivered through that HMO's counterpart Medicaid prepaid health plan, though the State has no direct role in the oversight of the Medicare HMO's services. The contracted HMO remains accountable to HCFA for Medicare services, and maintains a separate prepaid health plan contract with the State for Oregon Health Plan services.

By contrast, Minnesota Senior Health Options is pioneering an integration approach, in which HCFA has, in essence, allowed the State to act as its agent for Medicare. This allows the State to contract for a unified health system that encompasses both Medicaid and Medicare services. Participants are subject to a single enrollment process and the State oversees a single quality assurance system.

Dual eligibility raises a distinct set of design questions which have been addressed in detail elsewhere.[13] Some of the more significant questions are discussed below.

Is it Possible to Establish a Mandatory Program?

If a state wishes to include Medicare in a program for special populations, the program must be voluntary. This stems from the *unwaivable* Medicare requirement that Medicare beneficiaries have freedom to choose the providers of their choice.

It is possible, as in Oregon, to have a mandatory Medicaid managed care program that coordinates with Medicare for dually eligible persons, but the program must be constructed in a manner that allows enrollees to exercise their *Medicare* options. For example, if an Oregon Health Plan (OHP) member chooses a Medicare HMO for Medicare benefits, the member is enrolled in that HMO's counterpart Medicaid prepaid health plan[14] for OHP benefits. If the member opts for Medicare fee-for-service benefits, OHP still (with some exceptions) requires enrollment in managed care for Medicaid benefits.

Is Lock-in to a Managed Care Network Possible?

While lock-in[15] to a network is clearly possible in Medicaid managed care, its application to Medicare is more complicated. In a Medicare HMO, a Medicare beneficiary agrees to be restricted to using providers that belong to the network of the HMO he or she joins on a month-to-month basis, considerably shorter than the 12 months that may be required in Medicaid managed care. The same month-to-month lock-in was approved by HCFA for the Minnesota Senior Health Options program, but no precedent exists for a longer Medicare lock-in. However,

---

[13] Paul Saucier, *Managed Care for Dually Eligible Beneficiaries: Key Program Design Issues for States*, (Portland, ME: National Academy for State Health Policy, 1996).

[14] In other words the same managed care entity signs a contract with HCFA to provide Medicare services as a Medicare HMO and a separate contract with the State of Oregon to provide Medicaid services as a prepaid health plan. Since the same entity is providing both 'plans' of service that entity is referred to as the 'Medicare HMO' for Medicare services and the 'HMO's counterpart Medicaid prepaid health plan' for Medicaid services.

[15] A lock-in is the length of time an enrolled beneficiary must wait before changing plans without cause.

recent legislation provides for longer lock-ins including an annual lock-in for Medicare beneficiaries after 2002.[16]

Absent explicit Medicare lock-in to their Medicaid networks, some states (e.g., Arizona and Minnesota's PMAP program) have fashioned *de facto* Medicare lock-in to Medicaid plans by limiting their payment of Medicare cost sharing to the Medicaid plan in which the dually eligible person is enrolled. These states established this policy to encourage enrollees to use a primary care provider within the Medicaid plan's network. Network lock-in is an important issue because the primary care provider plays the major role in deciding what specialty and LTC services and which providers (through referral arrangements and admitting privileges) enrollees will use. Therefore, those that use a primary care doctor that is not part of the plan's network are more likely to obtain other services outside the network—including services that Medicaid pays for. However, this *de facto* lock-in is a controversial policy which HCFA has stated it will not approve in the future.

Is it Possible to have Capitated Medicare Payments Outside of Medicare HMOs?

As part of its waiver, Minnesota did get approval to have capitated Medicare payments made to contractors that are not necessarily Medicare HMOs. The payment is made directly to the contractor by HCFA, but is triggered by successful execution of a contract between the State and the contractor.

However, doing so requires a Medicare waiver, which is likely to take a considerable amount of time to obtain, given the still new and somewhat controversial nature of the approach. Several states, such as Maine, have begun or plan to begin enrolling dually eligible people with a Medicare fee-for-service component, with plans to capitate Medicare in the future, pending waiver approval. Either way, the main challenge becomes convincing dually eligible beneficiaries of the value of obtaining their Medicare and Medicaid services through a single entity, since beneficiaries are free to pursue Medicare services from any provider who will see them.

Summary

Managed care for the elderly and people with disabilities is still in its infancy. Though several Medicaid managed care programs have included older people and people with disabilities for some time, a limited amount of research has been completed, and it has not focused on comparative analysis of different program models. Thus, little consensus has developed regarding best approaches to take to

---

[16] Specifically, Title IV-A of the Balanced Budget Act of 1997 will allow for continuous enrollment and disenrollment for Medicare beneficiaries only during the first three months of each calendar year after 2002.

special populations, and states continue to design diverse programs consistent with individual state values, policy, experience, and infrastructure.

Chapter Two

Care Delivery

Robert Mollica
Neva Kaye

August
1997

NATIONAL ACADEMY
for STATE HEALTH POLICY

Chapter 2
Care Delivery

Introduction

Once the broad program outline of the managed care system is designed (as discussed in the previous chapter), the Medicaid agency then needs to decide how contractors should deliver care and communicate these expectations to them. If the contractors do not understand Medicaid's expectations they are very unlikely to meet them. This chapter seeks to assist state Medicaid agencies in this process by identifying specific strategies states use to define the care delivery system of programs serving the elderly and persons with disabilities through risk-based managed care. Of course, the information in the chapter on program planning in Volume II of this **Guide** also applies to this population. Indeed give the widely divergent needs of groups within these special populations, states developing programs for these populations may wish to devote even more effort to obtaining public input.

Information in this chapter is pertinent to all risk-based managed care programs that serve special populations (elderly persons and persons with disabilities)—regardless of the type of contractor, or the specific subpopulation served. This chapter will specifically address state options in areas of particular importance in serving elderly and persons with disabilities such as, access, care coordination, long term care services, marketing and enrollment, and quality.

For best results, a state should ensure that its care delivery expectations are reflected throughout the program—in the process used to select health plans, the contract under which plans will operate and the systems used to monitor managed care plans. For example, if a state decides to require contracted plans to provide a choice of two psychiatrists within 20 miles of every enrollee's home:

- the plan should be required to demonstrate this ability during the selection process—perhaps by supplying a provider list or a map showing the location of each psychiatrist in the network;
- the plan should sign a contract agreeing to meet that specific requirement;
- the state should establish monitoring strategies to determine whether the plan meets that standard—perhaps through monitoring complaints or periodic network reviews; and

- the state should develop corrective action strategies to improve the health plan's performance—perhaps through a corrective action plan or the imposition of contract penalties.

This chapter is based primarily on information gathered during site visits and interviews with state officials, managed care organizations and advocates in Arizona, California, New Jersey, Oregon and Tennessee. All of these states enroll some members of special populations into their Medicaid managed care programs.

Site Visit State Background

State	Year Risk-Based Program Began	SSI Enrollment as of June 30, 1996	Aged Enrollment as of June 30, 1996
Arizona	1982 Acute care 1989 Long term care (Both programs are mandatory.)	57,412	33,690
California	1983 Mandatory 1972 Voluntary	48,832	13,657
New Jersey	1985 Mandatory 1981-85 Voluntary	5,387	
Oregon	1995	11,799 (MH only) 31,311 (dental only) 31,671 (comprehensive)	7,871 (MH only) 20,909 (dental only) 16,759 (comprehensive)
Tennessee	1994	217,666	151,370

Access[1]

Most states use multiple methods for ensuring access for Medicaid managed care enrollees (see Volume II for details about many of these methods). But, there are access issues that are of particular concern to members of special populations. People with chronic conditions worry that they will be unable to access physicians and specialists familiar with their health and functional needs or specialists with whom they have a long standing relationship. Members of these groups also want services that maintain their functional capacity in their own homes or in residential

---

[1] Readers should be aware that Title IV-H, § 4705 of the Balanced Budget Act of 1997 requires states to have access standards (and monitor plan compliance with these standards) "so that covered services are available within reasonable timeframes and in a manner that ensures continuity of care and adequate primary care and specialized services capacity." Title IV-H also specifies that these standards "shall be consistent with standards that the Secretary first establishes within 1 year after the date of the enactment of this section." These new requirements will become effective on January 1, 1999.

settings. Finally, plans that serve members of these groups must accommodate the physical access and communication needs of special populations.

General Measures for Assuring Access

One of the major reasons Medicaid agencies turn to managed care is to improve and expand access to health services. A recent study found that people with chronic conditions among the general population often could not find a provider (11%), services were not available when needed (19%) or they could not get to the service(15%).[2] This situation combined with the reluctance of many providers to serve any Medicaid beneficiary could combine to make accessing care extremely difficult for Medicaid beneficiaries with chronic conditions.

Many of the states enrolling members of special populations into Medicaid managed care plans are doing so, at least partially, to improve access to care for these beneficiaries. Charts A and B[3] suggest that Medicaid agencies are responding to the needs of special populations, who have more complex needs than other Medicaid beneficiaries, and the access barriers some members of these populations have encountered. This attention may also reflect the lack of plan experience serving members of special populations.

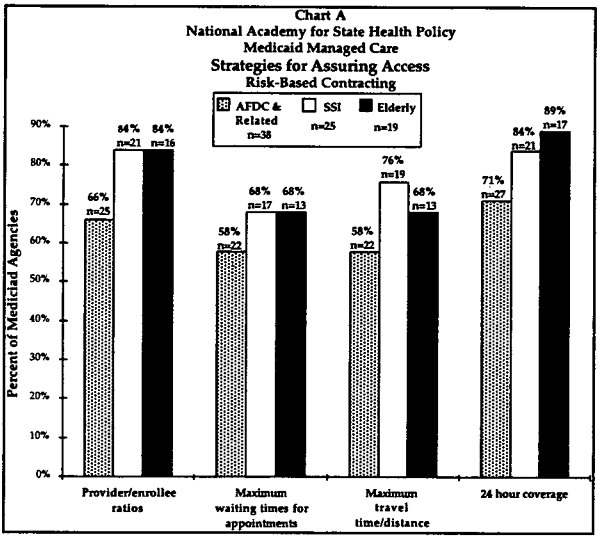


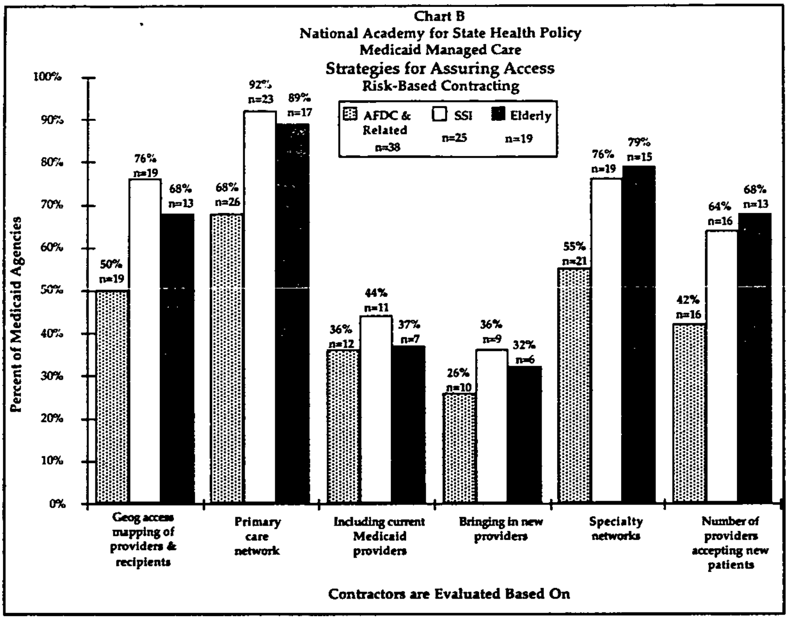
Chart A
National Academy for State Health Policy
Medicaid Managed Care
Strategies for Assuring Access
Risk-Based Contracting

This increased scrutiny is particularly apparent during the plan selection process and the use

---

[2] Catherine Hoffman, ScD. et al, *Chronic Care in America: A 21st Century Challenge,* (Princeton NJ: Robert Wood Johnson Foundation,1996).

[3] All charts in this Volume are based on state-reported information from the survey that forms the basis of Volume I and reflects program status as of June 30, 1996.



of strategies such as: using geographic access mapping of providers and beneficiaries; examining the plans primary and specialty care networks; and examining the plan's ability to make new providers available to enrolled beneficiaries. However, traditional measures such as the number of providers in relation to the enrolled population and time/distance measures, may not be appropriate to measure access for vulnerable populations. It is important to know whether the plan's providers are willing to care for people with disabilities and whether they have experience doing so. Consumers themselves may prefer to travel significant distances to see a provider that is experienced with the person's condition rather than a provider that is nearby but lacks this expertise. (For more discussion of all of the strategies identified in the charts please refer to the access chapter in Volume II of this **Guide**.)

Access to Primary Care Providers With Knowledge/Experience Caring for Members of Special Populations

Members of special populations sometimes need primary care providers who understand the connections between chronic conditions and primary health care needs. For example, women who are HIV positive should have PAP smears every six months. Unless a primary care provider is familiar with the needs of this group of women, this test may not be performed that often. Primary care providers with geriatric training may recognize the signs of some conditions, such as Alzheimer's disease, earlier than other providers.

States have responded to this need for primary care providers with knowledge and experience serving members of special populations in several ways. First some states allow plans to designate specialists as primary care providers to serve members of special populations. For example, the plans participating in Massachusetts' program for dual eligibles[4] will be able to use physicians with board certification in geriatric medicine or gerontology, as well as those with certifications in family practice or internal medicine. New York uses a similar approach and specifies that specialists may serve as primary care physicians for enrollees with complex needs.

Other states focus on ensuring that the primary care provider, regardless of specialty, has knowledge and experience treating persons that belong to special groups. For example, Pennsylvania requires plans to "...consider the special medical needs of each member when assigning a PCP to ensure that the member's PCP is trained and experienced in treating the members special needs." Similarly, the contractor for Wisconsin's Independent Care Program must "subcontract with providers with knowledge and experience relevant to the needs of the disabled population." Wisconsin Medicaid staff then prepared a report identifying providers that served many persons with disabilities in the plan's service area and reviewed a list of subcontracted providers submitted by the plan against that list.

In Oregon, members of health plans who are Medicaid beneficiaries must have the same access to providers as other plan members. In addition to meeting the community standard, contractors must also be able to meet the needs of the enrolled population. Under the administrative rules, contractors provide evidence that vulnerable populations have access to providers with expertise to treat the full range of medical conditions experienced.

Oregon's rules go beyond a generic access requirement. Plans are also required to develop plans and procedures for identifying members in need of interpreter services, members needing accommodations under the Americans with Disabilities Act (ADA), and to monitor, improve and manage risk in times of reduced provider capacity.

---

[4] 'Dual Eligibles' are those beneficiaries who have both Medicaid and Medicare coverage. Most elderly Medicaid beneficiaries are dual eligibles as are many Medicaid beneficiaries with disabilities.

Allowing beneficiaries to continue relationships with an established provider can also address the need for knowledgeable, experienced primary care providers. One strategy to ensure continuity is to enroll the beneficiary into a plan that contracts with the beneficiary's current provider. Many states include information about provider/plan affiliation in the enrollment material provided to the enrollee or provide access to a data base of provider affiliations during face-to-face enrollment counseling. The next step is to ensure that the enrollee can use the provider as the enrollee's primary care provider once the individual joins the selected plan. California, for example, specifies newly enrolled members wishing to maintain a relationship with a provider in the plan's network must be assigned to that provider.

Finally, the "conceptual framework" developed for the New England States Demonstration Projects for Dually Eligible Persons[5] recommends that specialists, registered nurses, nurse practitioners or care coordinators be able to perform many of the functions of a primary care practitioner. The framework indicates that consumers with minimal health needs and significant psycho-social needs will require extensive community-based services and coordination of health and long term care services which do not require a physician. The alternative primary care practitioner would notify the physician when a need for medical services occurred.

Physical Access and Communications Requirements
Some members of special populations have physical access and communication needs that plans must address. Some enrollees use wheelchairs, walkers, or need other assistance. Others may be blind, deaf, or need specially adapted communication equipment. To address the needs of many people with disabilities, plans will need special communication methods (interpreters for people with hearing impairments, TDD, resources for people with visual impairments, as well as assistance for people with cognitive impairments). Plans must not only provide these types of services, but they must also ensure that enrollees who use these services can access care.

Language requiring that all facilities comply with the ADA may be part of the contract boilerplate but there is often little review to ensure compliance. As Medicaid managed care programs enroll more people with disabilities, these requirements warrant increased attention. Contract language might be considered that describes how plans must review and document the accessibility of providers in their network.

---

[5] The conceptual framework describes a common approach to selected issues that will be taken by each of the six New England states in their waiver demonstration proposals to integrate care for dual eligibles.

Oregon's rules require that plans monitor compliance and determine whether members are receiving access accommodations, including steps that will be taken to remove barriers or accommodate members with special needs. Access includes street level access or ramp into the facility, wheelchair access to a lavatory, and wheelchair access to an examination room.

Once enrolled, plans need to be able to communicate with members who have special needs. States require plans to have TDDs, translate the handbook into braille, tape or large print. For example, Oregon's regulations require that contractors must have written procedures and trained staff to communicate with hearing impaired OMAP members via TDD/TTY.

Interpreter services are typically required of plans. Contracts usually require that plans have written procedures for communicating with members who do not speak English. Administrative offices, providers, and hospitals are required to have arrangements for interpreter services that are sufficient to ensure that practitioners can understand the member's complaint, to make a diagnosis, respond to questions and concerns and communicate instructions to the member.

Access to Specialists

Because members of special populations frequently have complex needs, access to specialists, particularly specialists with expertise in an individual's specific condition, is critical. Concerns in this area fall into two major categories: (1) the plan must be able to provide adequate access to specialists; and (2) individuals enrolled into the plan must be able to access those specialists. Many of the strategies discussed in the previous sections will also help address these issues (e.g., provider/enrollee ratios could be used to address the first concern, waiting times for appointments could be used to address the second, and enrollee surveys could address both).

In addition to the more general strategies, some Medicaid agencies use other strategies to ensure that adequate specialists are available to enrollees. For example, there may not be enough of a certain kind of specialist within a geographic area to provide adequate access. Arizona's contract requires that plans have networks adequate to provide all covered services. To meet these standards in rural areas, some plans must provide enrollees transportation to specialists located some distance from enrollees' homes. One plan makes a weekly trip to Tucson for clinic appointments and other plans transport members to specialists in both the Phoenix and Tucson areas. Similarly, as part of the plan selection process, Oregon requires plans to describe how they will obtain specialty care and incorporates that description into each plan's contract. Some plans developed arrangements with specialists outside their service areas to comply with the requirement.

Some states use other strategies to ensure that enrollees have adequate access to the specialists in the network. For example, New York and Oregon encourage plans to provide enrollees with complex needs with standing referrals to specialists. This allows the enrollee to see that specialist on an on-going basis without seeking a referral from the primary care provider for each visit.

Traditional Providers

Many long term care and behavioral health providers used by vulnerable populations have traditionally not been part of managed care networks. Many vulnerable members use clinics, health centers, community mental health centers and publicly funded non-profit community based organizations which are not part of plan networks. These providers may not meet existing plan credentialing standards and therefore do not participate in managed care networks. In several states, traditional providers have formed their own health plan. Federally Qualified Health Centers (FQHCs) in Massachusetts and Rhode Island organized HMOs which were licensed under state requirements. Health Centers in Oregon formed an alliance with the Oregon Health Sciences Center in order to continue to serve elders and people with disabilities through the Oregon Health Plan. In some instances, alliances between health plans and traditional providers meet mutual needs. Health plans often need to expand their general capacity in areas of a state and to add providers with experience serving Medicaid populations. Traditional providers need to retain members in order to remain viable. States may either require an alliance or contractual agreement or set bidding standards that create incentives for health plans to negotiate these arrangements.

Forming networks to deliver behavioral health and substance abuse services is also difficult. States often have a separate state or county operated network for serving low income and disadvantaged populations that is not generally used by privately insured people. HMO networks tend to include mental health providers with experience serving privately insured populations with acute mental health and substance abuse needs. These providers tend to have less experience serving people with chronic mental illness and substance abuse problems who, in the past, have been cared for by community providers. (Chapter 3 of this volume addresses these issues in more detail.)

In Oregon, most mental health services for Medicaid beneficiaries traditionally have been delivered by community mental health programs, predominantly operated by counties. Until 1995, those organizations rarely participated in networks of fully capitated health plans. In 1995 the State implemented a mental health service demonstration involving 25% of Medicaid beneficiaries and experimented with several behavioral health service delivery models, including management of those services by three capitated health plans. An additional model was an alliance of 15 county-owned programs operating independently of the capitated plans in those counties. The mental health demonstration was expanded to 100% of Medicaid beneficiaries on July 1, 1997. This expansion will result in the management of behavioral health services by additional fully capitated health plans.

Regardless of the contractual arrangements developed by capitated health plans and behavioral health care organizations, Oregon anticipates that existing community mental health networks will continue to provide a significant portion of those services to Medicaid beneficiaries. Prior to the 25% demonstration, traditional providers expressed apprehension that assumption of behavioral health service management by capitated health plans would seriously erode their client base. That fear, however, has diminished, and the community programs appear more willing to participate in both formal contracts and informal partnerships with fully capitated plans in the future.

Long Term Care Providers

Finally, managed care plans will need to develop relationships with a range of long term care providers. The type of arrangement will depend upon the scope of capitation. If long term care services are not part of the scope of services, referral and coordination will be needed with the long term care systems and providers of residential, home, and community based services. If the scope of service and capitation payment includes long term care, plans will need to contract with these providers.

Developing a network of community-based long term care providers may be difficult for plans. While plans have experience contracting with home health agencies, other agencies may be able to provide personal care and homemaker services more cost effectively. Home delivered meals, transportation, companion services, chore service and respite care can all be delivered by multiple community organizations.

The multitude of individual agencies that exists may discourage plans from contracting with these agencies. Plans can frequently sign one contract with one organization with multiple providers to obtain physician and other medical services. There is no identical provider consolidation in the community based long term care system. However, more loosely organized home care networks typically managed by local area agencies in aging (AAAs) and counties do exist in the current long term care system. These local, independent agencies are responsible for contracting, monitoring and quality assurance activities. However, contracting with these individual agencies could be time consuming and difficult for plans since standards for these agencies differ from those of health care providers. Many community agencies are not required to meet licensing standards common to health providers. States might be able to help address this issue by creating contract specifications that allow plans to contract with agencies that meet state requirements for participation in the state's home and community based services program.

In particular, plans without an existing network of community based long term care providers might consider contracting with the existing case management system in states with well-developed in-home programs rather than building a new system. Contracting with an organization that has an existing network of community providers will reduce the number of contracts that must be negotiated and monitored by the plan. Contracting with these agencies also ensures continuity of services for those already being served by the community based system and may enable the plan to begin providing these services quickly. However, community organizations need to be clear about the role of each organization—how enrollee needs will be assessed, service plans developed and services authorized. A community organization will also need to know what data it will need to provide to the plan and in what format. Although community organizations have to account for spending and report data to state agencies managing home and community based services (HCBS) programs, those requirements will most likely differ from plan requirements.

Special Considerations for Beneficiaries in Treatment at the Time of Enrollment

Many state contracts have specific provisions about the delivery of care to beneficiaries receiving active treatment on the date of enrollment. California's previously described requirement for plans to ensure that enrollees with existing provider relationships be allowed to continue those relationships addresses this issue. In addition, several states, such as Arizona and Oregon, make special efforts to ensure that plans know about the care beneficiaries are receiving before enrollment. In Arizona, if a member switches health plans, the current plan must notify the new plan of any care the enrollee is currently receiving such as, dialysis, need for organ transplant, or permission to receive out-of-area specialty services. Oregon compiles similar information as part of the enrollment process and forwards that information to the new plan. This enables the plans to better ensure access to needed services by identifying needs prior to enrollment.

Enrollees In Residential Facilities

Access to care may be especially difficult for beneficiaries in nursing homes or residential care facilities. Many times these beneficiaries may not be able to travel to see either the primary care provider or a specialist. Also, filling prescriptions may be problematic if the pharmacy the nursing home uses is not in the plan's network. Similar problems may arise if the DME or therapy providers used by the nursing home are not part of the plan's network.

Oregon specifically addresses delivering care to residents of nursing facilities and residential care facilities in its health plan contract. Oregon's contract requires plans to provide medication that is part of the scope of capitated services to "nursing facility and group home residents in a format that is consistent with the individual facility's delivery, dosage, and packaging requirements and Oregon law." This State also requires plans to generally cooperate with residential and nursing facilities.

Access to New Treatments

Treatment for some chronic conditions, such as AIDS, evolves rapidly. New treatments for other conditions are continually being developed. Medical science is continually improving its ability to perform transplants. Programs that serve persons with disabilities and the elderly must include mechanisms that allow enrollees to access these services when medically appropriate. This can be difficult (1) if the specific service was not included in the plan's scope of service or the capitation payment determination process, because it did not exist; or (2) if the use of the service or prescription drug that was covered in the contract and payment greatly increases because a new application was found for an existing treatment. In these cases the plan may be reluctant to provide the treatment because either the plan does not believe it is responsible for providing treatments that were not part of the contracted benefit package or because the plan does not believe that it is being reimbursed for providing the service in the manner in which it is proposed to be used.

States have a number of responses to this situation. Options include carving out the cost of new treatments or specified services such as transplants or protease inhibitors; providing supplemental payments; offering some type of risk sharing arrangement;[6] amending the contract and adjusting the capitation rate; and developing a process for determining when new services will be covered. California recently passed a law requiring that each health plan utilize an independent panel of three experts accredited by a private non-profit organization to review the validity of new experimental treatments for people with terminal conditions. The treatments would be covered if the panel finds the treatments are effective.

Importance of Defining Medical Necessity

As discussed in Volume II, it is important for Medicaid agencies to define medical necessity in their contracts to ensure that individual enrollees receive the specific services they need. This becomes even more important for persons with complex needs. In particular some states may want to consider creating a definition of long term care necessity or mental health care necessity to accompany the medical necessity definition or reviewing the medical necessity definition to determine whether it covers these situations.

In Oregon, home health benefits were authorized by case managers in the home and community based services system prior to the Oregon Health Plan. The benefits were used to support and maintain people with chronic conditions in their home.

---

[6] Risk-sharing models are described in more detail later in this chapter.

Responsibility for most home health skilled interventions and therapies was shifted to managed care plans. During the early phase of implementation, HMOs applied a "medically necessary" threshold to what they saw as overutilization. When services were reduced or terminated because they did not meet the medically appropriate criteria, beneficiaries complained. To help clarify the difference between fee-for-service practice, the supportive philosophy of the long term care system and managed care authorization based on medical necessity, Oregon has introduced the term "medically appropriate" which means a service is needed because of the medical condition though it may not be directly related to treatment of a medical condition. This clarification was expected to increase access to home health benefits as a Medicaid service.

In 1997, the Maine Department of Human Services proposed the "MaineNet" demonstration program, which will phase in the integration of acute and long term care services, using the following definition of medical necessity.

> Medically necessary means a services that is consistent with a beneficiary's diagnosis or condition and:
>
> - Is appropriate and effective for the diagnosis and treatment of pain, illness, disease or injury;
> - Includes preventive services that avoid or minimize the occurrence of pain, illness, infection, injury, disease, disability or other health condition; or,
> - **Maintains or improves functional quality of life or minimizes the deterioration of progressive disease.**

The definition of medical necessity is particularly important for vulnerable populations if the long term care benefits are not included in the scope of service and the capitation payment. This creates a requirement for managed care plans to make referrals to the long term care system when services may not meet strict medical necessity definitions yet they may be effective in preventing deterioration or reducing risk. Regardless of the definition of medical necessity, a plan may provide additional services at its discretion, and many do so. Of course, the application of the definition of medical necessity is closely tied to projected utilization and the capitation rate.

Highlights

- It is important to program success that the array of providers in plan networks is suitable to the needs of the population to be served and the scope of covered benefits.

- Strategies for measuring network adequacy include:
    - requiring the plan to demonstrate that it has enough providers to meet state established provider/enrollee ratios for specific provider types;
    - require plans to demonstrate their ability to meet state measured community standards that reflect the distribution or availability of providers for the population of the area, adjusted by the characteristics of the population to be served;
    - allow the plan to demonstrate how the network is appropriate to the population served.

- Plans may need to contract with community based organizations to meet some of the needs of special populations.

- Ensuring that plans contract with providers who have knowledge and experience that enable them to best meet the needs of special populations is important for program success.

- Plans may need the flexibility to assign specialist as primary care providers for some members of special populations or use standing referral to ensure that enrollees can have the access to specialist they may need.

- States should consider establishing plan contracting requirements that allow or encourage plans to build linkages with the existing network of home and community based providers rather than building a separate network.

Long Term Care Services

Enrolling vulnerable populations in managed care programs requires more attention to long term care than healthier populations. In federal fiscal year 1994, long term care services accounted for 35% of all Medicaid spending.[7] Spending on children and adults averaged $1,360 and $1,974 respectively while spending for blind/disabled adults averaged $8,421 and $9,437 for elderly beneficiaries. With few exceptions, elderly beneficiaries use more long term care than any other eligibility group. Medicaid acute care costs for elderly beneficiaries are lower than costs for blind/disabled beneficiaries since more elderly beneficiaries also participate in

---

[7] The Kaiser Commission on the Future of Medicaid, *Medicaid Expenditures and Beneficiaries: National and State Profiles and Trends 1984-1994*, (Washington, DC: Kaiser Commission, 1996).

Medicare. Long term care accounted for only 1.3% for adults and 6.7% of expenditures for children. But 43.3% of the spending for blind and disabled beneficiaries and 76.5% for elderly beneficiaries was spent on long term care.

Utilization also varies within eligibility categories. While use of Medicaid acute care services is similar between cash assistance and spend down cases, spending for long term care varies dramatically. Total spending for elderly spend down beneficiaries totaled $12,534 compared to $5,002 for cash assistance beneficiaries and spending for long term care accounted for $10,455 for elderly spend down beneficiaries versus $2,612 for cash assistance beneficiaries. Blind and disabled spend down beneficiaries spent $12,953 compared to $7,178 for SSI beneficiaries of which $7,927 was spent on long term care. These differences reflect the significant percentage of people who enter nursing facilities as private pay residents, exhaust their income and/or assets and become eligible for Medicaid. Ninety percent of the long term care spending for elderly spend down beneficiaries covered care in nursing homes. Most states spend more Medicaid funds on institutional long term care than community services. In 1992, the national average spending per older person was $735.83 for nursing home services and $199.23 for home and community based services.[8] Only Oregon spent more on residential and community care than institutional care. These figures suggest that effective managed care systems for vulnerable populations, especially those that also have Medicare coverage, must include long term care and linkages between acute care and long term care. In addition to focusing on long term care, managed care programs need an appropriate array of services—nursing home, residential, community and in-home services.

FY 1994 Medicaid Spending by Population

Category	Acute	Long term care	Total
Children	$1,269	$91	$1,360
Adults	$1,948	$26	$1,974
Blind/disabled	$4,776	$3,645	$8,421
Elderly	$2,207	$7,230	$9,437

Service systems for vulnerable populations require a full array of health, long term care, behavioral health and other services. The list of health services is well established in existing managed care programs (please refer to Chapter 3 of this Volume for more information on behavioral health Medicaid managed care). However, long term care and behavioral health services must be added if systems are capitated to deliver these services. If not, managed care plans will need referral

---

[8] Richard C. Ladd et al., State LTC Profiles Report, (University of Minnesota, 1995).

arrangements with traditional long term care providers and a system for coordinating activities.

Long term care is dominated by nursing homes in most states, yet policymakers have developed effective Medicaid waiver and state funded home care programs to serve beneficiaries in their homes or in supportive residential settings. Given a choice, beneficiaries prefer to remain in their own home, yet the supply of service providers and the entitlement nature of nursing home care makes it difficult for states to create sufficient incentives to use less restrictive and consumer-preferred services.

Balancing Service Supply And Avoiding Institutional Bias

Beneficiaries using long term care services benefit from in-home, community and residential services which reduce reliance on costly and often unnecessary institutional services. States should consider requiring plans to provide the full scope of services covered by the Medicaid state plan *and* home and community based waivers. Assisted living is or will be covered as a waiver service in 22 states. It offers beneficiaries who need a supportive living environment access to care 24 hours a day, seven days a week, particularly help with unscheduled needs at night. Facilities specializing in serving people with Alzheimer's disease allow these beneficiaries to live in cost effective, appropriate environments rather than enter a nursing facility during the early- and mid-stages of the disease. States will need to consider how to encourage plans to continue providing these beneficial and cost effective services to enrollees.

Plans may be creative and flexible in authorizing services which may not be specifically covered in the scope of services if the services are appropriate, cost effective and substitute for more costly care. For example, environmental modifications to a bathroom or kitchen may enable a frail older person to bathe, toilet or prepare meals without the assistance of a personal care attendant. Repairs to floors or replacing rugs may prevent a fall. Recruiting a neighbor or companion to visit periodically at meal times might ensure that the person is maintaining their nutrition. Capitation payments and incentives to maintain beneficiaries in their own home support this flexibility.

Creating Incentives for Appropriate Care

Capitation payments can create incentives for plans to use home and community based service providers. Arizona and Minnesota use different rating approaches to support these incentives. Arizona developed a blended rate for the Arizona Long Term Care Services (ALTCS) program which assumes that 40% of beneficiaries who are elderly or persons with physical disabilities will be served in residential settings or in their home. If fewer than 40% are served in non-institutional settings, plan spending will exceed the capitation. If more than 40% of the participants are served in non-institutional settings, the State has capped the savings that may be retained.[9]

Observers question whether this methodology creates incentives to underserve beneficiaries in order to increase profits. Several factors protect members from incentives to offer fewer services than people need, as well as monitoring/oversight activities that are designed to detect barriers to obtaining appropriate services. ALTCS contractors are at risk for costs which exceed their capitation payments. If contractors do not provide members an adequate level of services, the risk of admission to a nursing facility or a hospital increases.[10] Denial of care can lead to increased institutional expenses.

Second, case managers follow a cost effectiveness formula in developing HCBS services. Service authorizations are limited to 80% of the cost of care in a nursing facility. However, exceptions can be made to exceed the 80% cap. The provisions set guidelines against which spending patterns can be compared.

Third, functional assessments and level of care determinations are made by AHCCCS[11] staff not by the ALTCS contractor. Based on the assessment data and reports filed by ALTCS contractors, AHCCCS staff can identify under and over spending. Field staff review case records and service plans to determine whether the plan and service costs are warranted based on the member's assessment.

The Minnesota Senior Health Options program also created incentives to use residential and in-home services. The capitation system contains rate cells based on the level of impairment and the residence of the beneficiary. Separate cells are used for nursing home residents, beneficiaries who have moved from a nursing home to the community after a six month stay or longer, beneficiaries living in the community who meet the criteria for placement in a nursing home and other

---

[9] The 40% is a HCFA imposed cap. Arizona has requested approval from HCFA to raise this cap to 50%.

[10] This incentive may not be as strong for dual eligibles enrolled in an ALTCS plan (unless the ALTCS plan was also the beneficiary's Medicare HMO). In this case, since nursing facility charges are primarily covered by Medicaid and hospitalizations primarily by Medicare, the ALTCS plan (which provides Medicaid services) would typically have greater liability for nursing facility charges than for hospitalizations and, in theory, be more concerned with avoiding nursing facility stays than hospital stays.

[11] Arizona has several separate Medicaid managed care programs. The Arizona Health Care Cost Containment System (AHCCCS) provides medical care to those beneficiaries who are not eligible for long term care. ALTCS provides both medical and long term care to those who are eligible for long term care. These two programs are administered separately.

community based or well elders. The capitation payment for each group includes Medicare acute care, Medicaid acute care, and Medicaid long term care costs.

Participants who reside in the community and meet the nursing home level of care criteria earn a Medicaid payment for long term care services that equals the average spending for participants in the state's Medicaid home and community based services waiver. Participants who have lived in a nursing home for more than six months and who are relocated to the community earn the plan a rate that is *twice* the average HCBS rate. In addition the plan receives the PACE[12] adjuster—2.39 the AAPCC—for Medicare services for nursing home eligible participants who live in the community or who have moved to the community.

Other incentives are being developed in Texas which will pay lower rates for a period of time when a beneficiary is placed in a nursing home from the community or when a beneficiary who is "well" and not receiving HCBS services becomes frail and requires in-home care. This mechanism creates an incentive for the plan to conduct risk assessments and deliver adequate preventive care.

Highlights

- Opportunities for savings and care coordination are maximized and opportunity for cost shifting is minimized if the scope of benefits provided by the plan reflects the full range of needs of the population to be served.
- States need to consider how implementing a managed care program will impact long term care service providers and how to maximize enrollee choice of in-home, community, residential and institutional services as the individual's needs dictate.
- The structure of the capitation payment can create incentives to authorize in-home and residential services rather than institutional care.
- Safeguards are needed to ensure that beneficiaries are receiving an appropriate level of care in the community and to monitor incentives to underserve beneficiaries.

---

[12] The Program of All Inclusive Care for the Elderly (PACE) is a program designed to serve frail elderly beneficiaries of Medicaid and Medicare. PACE sites receive an adjusted AAPCC rate from Medicare.

Care Coordination and Case Management[13]

An analysis of Medicaid spending shows that vulnerable populations use a mix of health, supportive and social services. Persons with complex health care needs and needs which cross the health care and other service systems benefit from a process to coordinate services. Elderly persons often use both acute and long term care services. People with disabilities use acute care, long term care, attendant care, educational, vocational and housing services. The use of multiple provider systems adds to the complexity of serving vulnerable populations. Referrals require follow up. Treatment interventions need to be scheduled and coordinated. Office appointments should not conflict with delivery of in-home services. Physicians must be informed of any changes in health conditions observed by social workers and other professional and paraprofessional providers.

Depending upon the degree of integration between Medicaid and Medicare,[14] and acute and long term care services, the nature of the care coordination may vary. Plans that provide a full range of services members of these special populations may need potentially have greater control and ability to coordinate decision making since the majority of providers work for the same organization. As the authority for authorizing services is spread across multiple organizations, coordination becomes more difficult when each organization is accountable to a separate funding source. For example, an HMO nurse may refer a person for services from a community based organization. The community organization may have to complete its own assessment and apply different eligibility rules to determine whether services can be authorized. Funding may not be available and the person could be placed on a waiting list. The lack of access may affect the service planning of the referring organization or the involvement of separate organizations may delay the date for initiating services. If the HMO had authority over the funding, services could be initiated more directly and systems would be in place to coordinate the activity.

---

[13] The terms case management and care coordination are often used interchangeably. Case management means assessment, care planning, service authorization and monitoring of services over which the organization has direct control. In the case of managed care entities that usually limits these activities to coordinating medical care. Care coordination refers to activity related to accessing, delivering and monitoring services that are the responsibility of, or are controlled by, another organization.

[14] For those states that enroll dual eligibles into managed care coordinating Medicare services can be critical to coordinating over-all care to beneficiaries since Medicare is the primary payor of many acute medical services. In other words, the physician (who is usually paid by Medicare) drives the health care system through referrals. If the physician is not part of the plan's network it is likely that the physician will order Medicaid covered services that the plan might not cover either because the plan disagrees with the need or the physician fails to follow plan protocols for obtaining care.

Finally, coordination for vulnerable populations requires linkages to educational and other community based programs. Most older Medicaid beneficiaries are also eligible for Medicare but they are also eligible for services under the Older Americans Act, state funded home care programs, protective services, guardianship services, housing subsidies, fuel assistance, weatherization, community action program and others. While primary, acute and long term care services can be combined in one organization, people often benefit from other community services outside the scope of managed care such as, housing, educational or vocational services, social and community activities. Some enrollees may also benefit from more medically oriented services that may not be covered through managed care such as housing adaptations, nutritional programs, protective services, guardianship services, financial planning or management. Coordination and care management must link all these services to ensure that services complement on another and meet the needs of beneficiaries.

Description of Comprehensive Care Coordination

Since states and plans have limited resources and not all elderly or persons with disabilities need (or want) care coordination, these systems first need to identify people whose condition warrants these services. Potential people in need of these services could be identified during the enrollment process, through provider and family referral, or self-identified. Therefore, members of these groups need to be aware of the availability of these services and, providers and enrollment staff also need to know what criteria members of special populations will need to meet in order to participate in the care coordination program. Those beneficiaries that need these intensive services should then be assessed to identify both medical and social conditions and resulting needs. Based on the assessment a comprehensive plan of care is developed that includes medical, behavioral and social/supportive services.

The most important aspect of care coordination is the assignment of responsibility to specific persons for coordinating, with the beneficiary, family members, or representatives, the plan of care. The plan of care should be comprehensive. The staff member or team performing these functions is responsible for assessing needs, ordering/authorizing in-plan services, referring or otherwise helping beneficiaries access important out-of-plan services, monitoring services and reassessing to make sure the full plan of care is implemented. Managed care entities need to consider how to incorporate the medical case management activities of the enrollee's primary care provider with the care coordinator (if different than the physician) to ensure comprehensive care. Managed care programs that do not directly deliver long term care services will need to place greater emphasis on coordinating with systems and providers outside the managed care entity. However, the goal of care coordination should be the same for all programs—implementing a plan of care that addresses the full range of member needs.

State Medicaid Experience

States recognize the need for the type of care coordination and case management[15] described in this document for serving some Medicaid beneficiaries who are elderly or have a disability. Care coordination and case management were identified as important services in all five states visited to produce this **Guide** (Arizona, California, New Jersey, Oregon and Tennessee), although the scope and definitions varied considerably. These services took several forms—utilization review, diagnosis and disease based case management and a broader social and medical case management. Plans in several states indicated that the health conditions and needs of elderly and disabled Medicaid beneficiaries were similar to the needs of some commercial members.

Assessment

One broad function of care coordination is to first identify beneficiaries who need coordination and then ensure that medical and support services are appropriately integrated across providers and settings. There exist two types of assessments. The first type assesses the individual to determine if that person is a candidate for care coordination services and the second begins the actual care coordination process by identifying the medical, long term care, and social needs of the individual. If the program is similar to the Community Medical Alliance Program in Massachusetts that serves only those with intense needs (severe physical disabilities and active AIDS) the state or contractor may wish to combine the two assessments. But, if the program is like Maryland's and enrolls a broad segment of the Medicaid population the state or plan may wish to use a short assessment tool to identify potential candidates for the service and only perform an in-depth assessment for those found eligible for the service.

Working with the Health Care Financing Administration's Medicaid Managed Care Technical Advisory Group, the National Academy for State Health Policy prepared a framework for developing contract specifications for dual eligibles, who are almost all either elderly or persons with disabilities. Drawing on the assessment instruments developed by state home care programs, this framework recommends that in-depth assessment tools include a complete medical history with medications, a section describing functional status, physical well-being, mental health status, history of tobacco, alcohol and drugs use, formal and informal supports, assessment of the willingness and capacity of family members to offer support and the identification of unmet needs. Other tools include a review of environment to identify potential risks or threats to health and safety.

---

[15] As previously discussed these terms are frequently used interchangeably. In general this document defines case management to relate more to coordinating medical services and care coordination to coordinating both medical and non-medical services.

Care Coordination Process
Under a demonstration program proposed by the Massachusetts Division of Medical Assistance, Senior Care Organizations will form primary care teams consisting of a primary care physician, a nurse practitioner or registered nurse and a geriatric services coordinator (GSC). The GSC would be a staff of the existing community long term care system or Aging Services Access Points.[16] Beneficiaries identified as at risk during an initial assessment would receive a comprehensive geriatric assessment, including an in-home assessment by the team.

Senior Care Organization contractors would be responsible for ensuring linkages among all subcontractors (acute, specialty, mental health/substance abuse and long term care). In addition a process for making referrals, recording and tracking the results of referrals, sharing clinical information, tracking enrollee transfers from settings and a centralized enrollee record will be required.

Plans in California and Tennessee have developed procedures to identify risk and devise care coordination plans even though they are not required by state contracts. Coordination in these plans extends beyond referrals from primary care physicians to specialists and includes making sure durable medical equipment and supplies are available, appointments and treatment plans involving physicians and home health services are coordinated, assessments are performed and treatment plans are modified as appropriate. Coordination also means working with hospital discharge planners, therapists and home health providers as well as case managers and providers in the community based services programs.

Exceptional Needs Care Coordinator—Oregon
The Oregon Health Plan has perhaps the most defined care coordination service. Health plans are required to create Exceptional Needs Care Coordinator (ENCC) positions. Plans indicated that they were very actively involved in developing the role and function of the position. ENCC services are designed to:

- identify members who have disabilities or complex medical needs;
- provide assistance to ensure timely access to providers and capitated services;
- coordinate services with providers to ensure consideration is given to the unique needs in treatment planning;
- assist providers with coordination and discharge planning; and

---

[16] Aging Services Access Points, formerly Home Care Corporations, are non-profit community-based organizations a majority of whose board members are over 60 years of age. Many of the State's corporations also serve as Area Agencies on Aging (AAAs).

- coordinate community supportive and social service systems linkages with the medical system.

Beneficiaries needing care coordination are identified during the enrollment process. Enrollment counselors complete a Continuity of Care Referral for members receiving long term care services from the aging network, durable medical equipment or other services that must be continued. The Continuity of Care Referral is reviewed by the ENCC for potential medical needs and sent to the primary care physician.

The ENCC role has two dimensions: case management of medical services and coordination between the medical and social service systems. The medical case management component covers all services included in the capitation payment and is designed to assure that "members obtain health care services necessary to maintain physical and emotional development and health. Medical case management includes a comprehensive, ongoing assessment of medical and/or dental needs plus the development and implementation of a plan to obtain needed medical or dental services that are capitated services or medical case managed services and follow-up, as appropriate, to assess the impact of care."[17]

ENCC services are available to all Medicaid beneficiaries who are elderly, have a disability, or are children in foster care. ENCC services may be requested by members, their representatives, a physician or other medical personal, or the member's long term care system case manager. Some plans also use information such as hospital admissions to identify those who might need care coordination. Staff providing ENCC services must have skills and training in the unique needs of aged, blind and disabled members. Requests must be responded to by the next work day following the date of the request. Medical practitioners must also be informed of the availability of ENCC services. Services are also available for members who exhibit inappropriate, disruptive or threatening behavior in a practitioner's office when they are related to the member's disability. In most plans, the beneficiary's primary care physician (PCP) is the focal point for all services.

Plans use ENCCs as a resource to sort issues out and manage the delivery of services. In one case experienced by Regence HMO Oregon a grandmother in a Cambodian family who had a stroke and received ventilator care was being cared for at home by her daughter. The daughter attempted to order a hospital bed, a hoyer lift, a specialty chair, and IV equipment. In addition, she took supplies from the hospital at discharge and ordered excessive supplies from providers. The ENCC convened a meeting with the daughter, the long term care case manager, the home health agency, and the respiratory therapy agency. They agreed on one supplier and the

---

[17] Oregon Health Plan Administrative Rules, 410-141-000.

home health agency developed a list of supplies that would be needed for the month. The daughter trusts that the ENCC will obtain services and supplies when needed.

Plans report that providers often call ENCCs with referrals to solve problems, often for people who are abusive in the office or emergency room. The ENCC tries to learn more about the cause of the behavior. Sometimes a change to a primary care physician who is more sensitive and effective in communicating is proposed. Other interventions require that staff from a facility or a case manager from a program that is serving the member escort the member to an appointment. In other cases the ENCC may write a letter to the member outlining guidelines to be followed. ENCCs have developed restrictions for members making repeated emergency room visits for chronic neck and headache pain in order to obtain drugs. The restrictions generally limit the member to one emergency room, one pharmacy and doctor accompanied by a referral to a mental health chemical dependency provider.

ENCCs have also arranged wood delivery and installation of phone systems. The role has created a shift to a psycho-social focus compared to the traditional medical focus of commercial plans. Citing the broader scope of services and role accompanying the Oregon Health Plan compared to its commercial business, one HMO official said, "NCQA made us a better company but OHP has given us heart. Education empowers people. ENCCs have people sign contracts after reaching agreement with a beneficiary to follow a treatment plan. That never happened under the old system." The fee-for-service system was described as too complicated to develop one point of access to a range of services.

Plans reported that the role of the ENCC was important because of the needs of the populations served and the confusing nature of managed care for some members. One plan suggested that the function was included in state law because advocates were concerned that fragile members would be lost in health systems designed for healthier commercial members. The plan noted that managed care has dealt with fragile members for many years although the position has helped create a central focal point for contact within plans.

The ratio of ENCCs to members in Regence HMO Oregon is 1 to 4,000 but each carries an active caseload of around 100. ENCCs in the plans have developed good relationships with the state ombudsman and frequently communicate with State Ombudsman office staff on specific cases.

Regence HMO Oregon invited staff from programs serving people who are seriously and persistently mentally ill, developmentally disabled, people with disabilities and older people to learn about the needs of different populations and to train ENCCs. Registered nurses with special skills were hired. The role has a greater social orientation and a consumer view of access to health care services than traditional medical case management. Health plans advise any plan to implement an ENCC position even if it is not required. "Health conditions can't be isolated and primary care alone will not make a person well when they are poor, have communication and housing problems and other traumas. A broader approach is needed to pull all components together."

Plans also conduct medical case management which may be combined with the ENCC function or handled separately. Regence HMO Oregon has established twelve criteria for case management referrals. They include long term ventilator dependency, members whose anticipated and/or cumulative claims exceed $50,000 a year, members with a pattern of repeated hospital admissions for the same or like diagnosis, three emergency room visits in three months, members with multiple providers and resources use, all transplant activity, DME purchases over $5,000, requests for private or two intermittent home visits per day, convenience ambulance transports, medically necessary services for members without benefits or whose benefits are nearly exhausted, requests for services that are not least costly, and out of state non-contracted services.

Care Coordination in CalOPTIMA

Another approach was described by CalOPTIMA, which administers the Medicaid program in Orange County, California through contracts with multiple health plans. CalOPTIMA staff indicated that case management procedures[18] should be developed at the beginning of a program because of their value. Initially, some CalOPTIMA plans equated case management with utilization review. CalOPTIMA mailed a survey to each of its members to identify beneficiaries receiving home health services, awaiting scheduled surgery, or members receiving supplies. Smaller, less experienced Physician Hospital Consortiums were not sure what to do with the information initially. The survey also increased expectations from members who expected follow up. CalOPTIMA officials reported that over time, plans saw the need for and benefit of coordination.

CalOPTIMA case management staff provide coordination for the elderly and persons with disabilities. The coordination function includes trouble shooting, liaison to carved out services (mental health, dental) and specific activities for high risk members which includes facilitating access to services, monitoring medications, home safety, compliance with treatment plans and coordination with long term care providers. CalOPTIMA uses registered nurses as case managers and they are assigned to specialty areas. The role also includes resolving operational problems and developing memoranda of understanding. CalOPTIMA requires that plans

---

[18] CalOPTIMA and the Arizona Long Term Care Cost Containment System both use the term 'case management' to mean what has previously been described in this **Guide** as 'care coordination.' Therefore, these two sections also use the term in the same way.

develop a case management system that includes procedures for assessment and care planning.

CalOPTIMA has developed its own case management manual, conducted workshops for plans and will perform focused case management audits to ensure that members with special needs are being addressed. Forms and procedures for making referrals, conducting an assessment and developing a plan of care are specified in the policy manual. The assessment process evaluates the member's strengths, problems, prognosis, functional status, needs and short and long term goals. Information is gathered through phone calls, medical record reviews, multidisciplinary team meetings, consultation with the primary care physician and consultation with the utilization review staff. Care planning guidelines require that members be active participants in the process within their capabilities. The manual also sets parameters for intervention according to "domains." The domains include medication related issues, health access, safety, treatment/outcomes, and new onset/diagnosis. Each domain has problem labels, intervention options and expected outcomes to guide case management activity.

Collaboration with agencies and advocacy is explicitly encouraged. CalOPTIMA formed a work group to deal with coordination. Issues addressed included dealing with customized durable medical equipment and approving incontinence supplies. Plans now approve a six month supply of most supplies but because of changing eligibility, the supplies are dispensed monthly.

The Arizona Long Term Care System
In the Arizona ALTCS program, the role of the case manager is essential in coordinating delivery of the acute and long term care services and adjusting services based on health and functional changes. The ALTCS case management manual describes case management as "the process through which appropriate and cost effective medical, medically-related social services, and mental health services are identified, planned, obtained and monitored. The case manager will assist the individual in maintaining or progressing toward his or her highest functioning level through the coordination of all services, both formal and informal."

The ALTCS case management manual states that the case manager is responsible for coordinating services with the primary care physician. The services which case managers must record in the service plan include institutional services, home and community based services, behavioral health, durable medical equipment, medically necessary transportation, therapies, individual/group and/or family therapies. The manual requires that case managers contact the primary care physician to discuss changes in the client's condition and to determine whether any changes are needed in the physician's order concerning the level of care, care plan, medical services, behavioral health services, prescription drugs or medical equipment. Case managers use the Preadmission Assessment Survey as a guide in determining when to contact the physician. Disagreements between the case manager and the physician are referred to the contractor's medical director. Physicians are involved in decisions or recommendations to transfer or terminate a member.

The process for developing and coordinating plans of care for individual members of special populations who are dually eligible for Medicare and Medicaid varies depending upon the member's choice of Medicare providers. While ALTCS is responsible for acute care for its members, most elderly members are also eligible for Medicare and may receive care paid by Medicare outside the approved ALTCS plan of care. The ALTCS capitation rate assumes some care will be billed to Medicare. Staff functioning in a case management role need the authority to identify members at risk, to conduct an assessment, to make referrals and involve appropriate network and external professionals and to use the flexibility of the capitation payment for unique interventions that are not part of the required service package.

Based on the experience of states and the health plans interviewed, case management is a component that assists in achieving the goals of managed care for vulnerable populations. It helps people with multiple health and social service needs and provides a vehicle for identifying and resolving problems for members and providers. While Medicaid and Medicare recognize the importance of coordination and case management, the structure of the two programs often make it difficult to achieve the goals of coordination and case management. In a sense, these conflicts add to the importance of the function yet make it more difficult to implement.

Case management for the elderly and persons with disabilities in managed care settings cuts across payers, programs and services. Since older people are eligible for multiple programs, care management and coordination extend beyond Medicaid. While the form of delivery changes based on the enrollment policy of the state Medicaid agency and the beneficiary's choices under Medicare, the need and functions are the same. What differs is the locus of responsibility and the scope of authority. Organizations receiving funding from a number of programs have increased ability to make decisions with the beneficiary and their family. Coordination is needed with organizations outside the plan offering services related to the person's needs.

Coordinating Medicare and Medicaid

As previously discussed many members of special populations are dual eligibles. Because of this situation many states are becoming interested in enrolling dual eligibles into Medicaid managed care programs. Those states that intend to do so, as well as, the few states who currently operate programs for dual eligibles need to be aware of the complications Medicare eligibility can introduce into care coordination for Medicaid beneficiaries who are dual eligibles.

Coordinating services is complicated for dual eligibles who are covered by two payers (Medicaid and Medicare) and receive both acute and long term care. Coordination varies by the type of systems dually eligible beneficiaries may enter. While Medicare and Medicaid each seek to promote continuity and coordination, states experience difficulties coordinating services for dual eligibles. The difficulties vary with the type of managed care arrangement. There are multiple arrangements involving Medicaid and Medicare, as illustrated by the following table.

Managed Care Arrangements For Dually Eligible Beneficiaries[19]

Arrangement	Examples	Implications
Enroll in same plan for Medicare and Medicaid health services	Arizona, Oregon, Minnesota PMAP	Permits maximum coordination of care for health services.
Enroll in same plan for Medicare and Medicaid health and long term care services	Arizona, Minnesota MSHO	Permits maximum coordination of care for health and long term care services.
Enroll in Medicaid plan; Medicare fee-for-service; no out-of-network cost sharing	Arizona, Oregon, Minnesota PMAP	Considerable coordination at the provider rather then HMO level since network physicians can follow Medicare fee-for-service guidelines.
Enroll in Medicare HMO with Medicaid fee-for-service	Arizona, California, Oregon	Because of the 30 day Medicare lock-in, members will use providers within the HMO network for most health services.
Enroll in different HMOs for Medicaid and Medicare	Arizona	Conflicts occur with overlapping benefits and assignment of two physicians.
Enroll in Medicaid plan with Medicare fee-for-service; no limits on out-of-network use	California, Tennessee	Opportunity to coordinate care is limited to Medicaid only benefits since members can use any provider for Medicare.

The complexity of coordination varies with the type of arrangement. Plans providing both Medicare and Medicaid services have a broader scope of authority

---

[19] It is important to note that Minnesota has two managed care programs that serve the elderly. The Prepaid Medical Assistance Program (PMAP) is a mandatory program for the elderly and TANF populations and has operated since 1985. It does not include nursing facility or home and community based waiver services. Dual eligibles are locked into the network for 12 months for all services, except the enrollee may go out-of-network for Medicare services if the enrollee is willing to pay the Medicare co-pays. The Minnesota Senior Health Options (MSHO) is a voluntary alternative to the PMAP for dual eligible beneficiaries. This program provides both Medicaid and Medicare services. Enrollees may disenroll from the plan or program on a monthly basis but are locked into the plan's network for that month for all services—neither Medicaid nor Medicare will pay for any portion of services obtained outside the plan's network.

and therefore have greater ability to control the full scope of services. Coordination is easier since the plan can develop multi-disciplinary teams or other mechanisms for making referrals, authorizing services, monitoring delivery and outcomes and adjusting service plans based on reported changes in the beneficiary's condition. Medicare HMOs are required to coordinate services for beneficiaries. The Medicare manual requires that plans promote continuity of care which is described as "the degree to which the care needed by a patient is coordinated effectively among practitioners across provider organizations over time. This concept emphasizes:

- coordination of health care services among primary and specialty care physicians;
- coordination among specialists;
- appropriate combinations of prescribed medications;
- coordinated use of ancillary services, including social services and other community resources;
- appropriate discharge planning; and
- timely placement at different levels of care, including hospital, SNF [skilled nursing facility], and home health care."[20]

Services provided to members should be structured in a manner which assures continuity. Medicare rules indicate that continuity can be achieved "by having a primary physician responsible for coordinating a member's overall health care and by maintaining record keeping systems through which pertinent information relating to the health care of the member is accumulated and readily available and shared among appropriate professionals and available for external peer review. Make arrangements for the physician or other health professional coordinating the members overall health care to be kept informed about referral services provided to members."[21]

The manual requires that HMOs "employ systems to promote continuity of care and case management. This could include development of a plan for the overall treatment of each patient. This plan could cover the full course of illness and related medical conditions. It should also address issues related to treatment at the proper level of care and ensure adequate follow-up."

---

[20] Medicare manual, § 2304.

[21] Medicare manual, §2304.

Highlights

Effective care coordination systems include the following components.

- A multi-disciplinary approach to assessment, care planning, and care coordination is designed that assigns responsibilities to members of the team based on individual care needs.
- Procedures for coordinating the medical and social service needs that involve working with area agencies on aging, developmental and behavioral clinic services and other community-based programs appropriate to the population to be enrolled.
- Procedures for identifying and assessing high risk enrollees.
- Steps to coordinate activities when multiple care coordinators are assigned to a beneficiary by different programs and agencies.
- Recognize and address the multiple variations for participation in managed care and fee-for-service programs among beneficiaries.

Marketing and Enrollment[22]

Effective managed care begins with marketing, outreach and education to beneficiaries. (Please refer to the chapter on consumer protection in Volume II for more information on enrollment and disenrollment.) Managed care works best when beneficiaries understand their choices and select a plan based on their health needs and past relationships with a range of health and, if included in the managed care program, behavioral health and long term care providers. Once a plan is selected, beneficiaries need to know how the plan operates, what is expected of members and what members can expect from their plan. A number of activities are necessary to acquaint beneficiaries with managed care. State agencies, brokers, plans, advocates, providers and beneficiaries all have roles in outreach, marketing and education to assure an effective managed care system. Consumer representatives stress the importance of face to face meetings, rather than mail or phone contact, to conduct enrollment.

---

[22] Much of the information in this section was derived from: Jane Horvath and Neva Kaye, *Enrollment and Disenrollment in Medicaid Managed Care Program Management*, (Portland, ME: National Academy for State Health Policy, 1996). and Robert L. Mollica, et al., *Consumer Protection: Lessons Learned from States*, The Kaiser-HCFA State Symposia Series (Portland, ME: National Academy for State Health Policy, 1996).

Beyond identifying and contacting beneficiaries to educate them about the program and the choices they must make to participate, procedures are required to help beneficiaries, once enrolled, schedule needed appointments and ensure that they access services. Educational activities undertaken through the counseling and enrollment process, and by health plans once a member is enrolled, help beneficiaries learn how to use the managed care system.

Several states report that enrolling beneficiaries, particularly in mandatory programs, has been easier than educating new members about managed care. Education efforts in several states with mandatory managed care programs have shifted emphasis from choosing a physician or plan to educating about how to access care and how to use the managed care system. States and plans report that they have found that they cannot rely on physicians to educate members. One of the major reasons it can be difficult to use physicians to convey information is that physicians, for a number of reasons, often spend too little time with members during office visits to engage in educational activities.

To assist provider's education efforts, some plans now locate their staffs in physician waiting rooms to work with members. Also, Ohio uses a mentoring process for its AFDC (TANF) population where enrollees themselves contact other members and encourage prenatal visits and immunizations for children. Similar arrangements could work to help members of special populations access services. Minnesota and Ohio identified the importance of working with community social services organizations and courts to educate staff of these organizations about how beneficiaries use HMOs. For example, members were sometimes referred to non-plan providers for court ordered treatment. If properly informed about managed care, ancillary agencies, such as social service agencies, can help contact and inform hard to reach beneficiaries about the importance of accessing health care services.

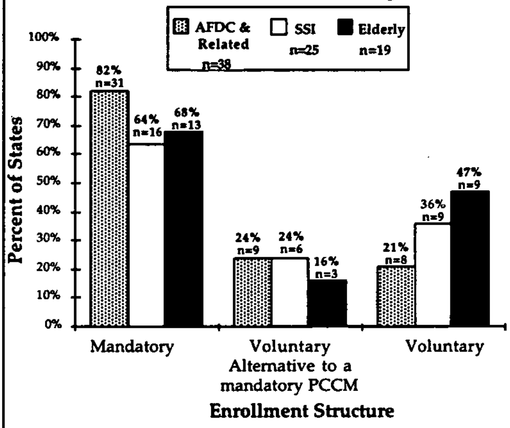
State Enrollment Policy Choices

The enrollment and outreach processes should fit within the overall enrollment structure of the program. In other words, the enrollment process needs to ensure that beneficiaries understand their enrollment options. These options vary from state to state. Important components of these options include:

- Will the program be voluntary or mandatory?
- Which subgroups within a mandatory population are excluded from or may opt out of the managed care program?

States generally select one of three options for the mandatory or voluntary nature of the program. (1) States may implement a mandatory program under which beneficiaries that belong to the population served by the program must select a health plan option. (2) States may implement a voluntary program under which beneficiaries that belong to the population served by the program may choose a health plan or remain in the fee-for-service system. (3) States may implement a mandatory managed care program under which beneficiaries must select a health plan or a primary care case management provider.[23] As shown by Chart C,[24] states appear to be divided as to which of the options to select—even within the same state. For example, some states may have a voluntary HMO program and a mandatory mental health carve-out program. Or, as in Utah, a program may be voluntary in the rural areas of the state and mandatory in the urban areas.

Chart C
National Academy for State Health Policy
Medicaid Managed Care
Enrollment Policies
Risk-Based Contracting



Note: The same state may operate both a mandatory and a voluntary program.

---

[23] As previously discussed states may currently establish voluntary programs without need of a waiver. Also, Title IV-H of the Balanced Budget Act of 1997 will, as of October 1997, enable states to establish mandatory programs without need of a federal waiver for all Medicaid beneficiaries except: dual eligibles, certain children with special health care needs and (under most circumstances) American Indians.

[24] All charts in this Volume are based on information reported by states and reflect program status as of June 30, 1996. For more information about an individual state's policies please refer to Volume I.

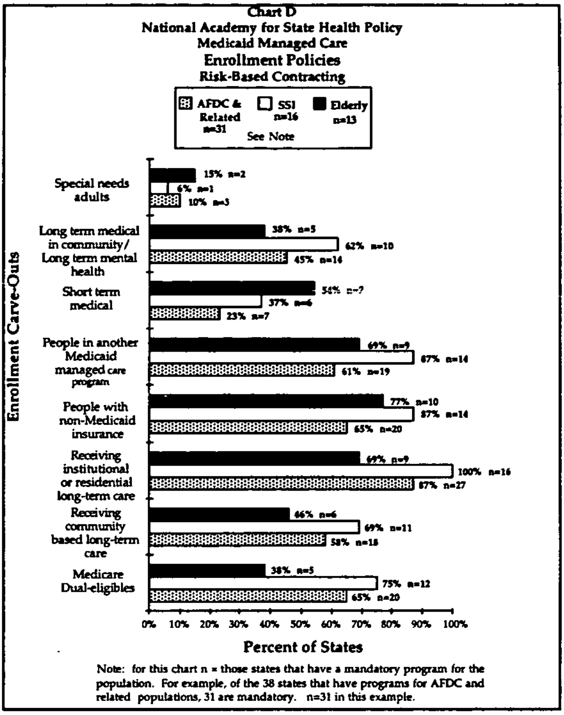


Chart D
National Academy for State Health Policy
Medicaid Managed Care
Enrollment Policies
Risk-Based Contracting

Note: for this chart n = those states that have a mandatory program for the population. For example, of the 38 states that have programs for AFDC and related populations, 31 are mandatory. n=31 in this example.

The next level of decision making is which members of populations that are otherwise eligible from the program will either be given the opportunity to opt out of a mandatory program or be excluded from enrollment (Chart D). For example, states frequently allow people who are currently under treatment to delay enrollment until after the treatment is completed or until the provider can transition the beneficiary to a plan provider (short term medical). Another group that is frequently carved out are those who are receiving institutional care. States may decide to carve-out these individuals because the state feels that the individual's care is already being coordinated by the institution. Many states also carve-out dual eligibles (those eligible for both Medicaid and Medicare) due to the administrative difficulties of coordinating the two programs described throughout this volume.

Enrollment Process

The process of enrolling beneficiaries into Medicaid managed care plans is a critical component of providing access to quality health care services. States have built their systems with the expectation that beneficiaries who know what they need and prefer and who voluntarily select a plan that meets those needs are more likely to be satisfied with the plan and to use services as they are needed. Beneficiaries need a process that fully informs them about the availability of plans and their networks, the implications of managed care and the procedures for effectively accessing services when needed. This is true regardless of the decisions states have made regarding the voluntary or mandatory nature of enrollment into the program.

The first step toward Medicaid managed care is eligibility for Medicaid but enrollment in a health plan is generally agreed to be a discrete function in which beneficiaries learn about managed care and how to use it and select a plan that best suits their individual needs. These processes are particularly important—and particularly difficult for older persons and persons with disabilities.

Some states have allowed health plans to conduct their own marketing and enrollment. However, abuses and concerns that beneficiaries were not aware of the full range of available plan options led many of those states to use state employees or independent enrollment brokers to conduct these functions.[25] Those states that enroll special populations have been especially concerned that members of these populations receive complete and understandable information during the enrollment process. This is supported by the fact that 62% of the 16 states that enroll SSI beneficiaries use an enrollment broker while 47% of the 38 states that enroll AFDC beneficiaries use a broker.

Arizona does not allow plans to conduct any marketing or provide incentives for people to enroll. Plans are allowed to conduct outreach activities or market incentives that change care seeking behavior.

Addressing Continuity

When vulnerable populations enroll in a managed care program, a process that identifies services currently being provided and/or assesses risk helps promote continuity of care. The identification of members with ongoing care needs can be accomplished by counselors or brokers during the enrollment process or by plans. Tools to identify members who are at risk that are used by the health plans may be designed by the state agency and included in the contract or designed by the plan, subject to state agency approval. The *Framework for the Development of Managed Care Contacting Specifications for Dually Eligible Adults*[26] recommends development of a form and a process to identify complex needs. State contracts might require that beneficiaries who are at risk be seen by a primary care physician within a specified period after enrollment e.g., five days. Possible indicators of a

---

[25] Readers should note that probably due to similar concerns on the part of the federal government, Title IV-H, §4707 of the Balanced Budget Act of 1997 prohibits both direct and indirect 'cold call' marketing by managed care entities. This prohibition applies to contracts entered into or renewed after October 1, 1997.

[26] This document was produced by The National Academy for State Health Policy in conjunction with HCFA 's Medicaid Managed Care Technical Advisory Group.

member with complex needs might include:

- poor self-reported health status;
- use of long term care services;
- chronic health conditions;
- functional impairment in activities of daily living;
- cognitive or emotional impairments;
- recent hospitalizations or admissions to a nursing facility or assisted living facility;
- use of prescription drugs; and
- recent significant life event (death, relocation).

State Strategies for Transferring Information About Health Services Upon Enrollment

During the open enrollment period in Arizona, transition coordinators at each plan monitor rosters of people entering and leaving the plan. Information is shared among plans that identifies members who are hospitalized, those who have recent or scheduled surgeries, chemotherapies underway, durable medical equipment that has been ordered and members who are receiving care management or who are noncompliant.

Choice counselors in Oregon complete a Continuity of Care Referral (CCR) form when members have special or complex medical or social needs requiring the immediate attention of the health plan. The CCR is sent to the Managed Care Organization (MCO) and alerts ENCCs to the services being received by members or needs which must be addressed. The form is reviewed by the ENCC for potential medical needs and sent to the primary care.physician.

Who Enrolls Beneficiaries

In general, enrollment can be performed by several different groups: state income maintenance workers who are responsible for determining welfare and Medicaid eligibility (Missouri), Medicaid employees (Utah), interagency agreements with another state agency (in Oregon, the Senior and Disabled Services Division enrolls aged and disabled beneficiaries through its field offices and Area Agencies on Aging), county employees (Minnesota) or staff of a private contractor (New Jersey, New York City, Ohio). If state or county employees are used as brokers, states recommended that training, supervision and management be conducted by the Medicaid agency rather than by cash assistance eligibility workers. Eligibility workers have had competing responsibilities which makes it more difficult for those workers to master the complexities of Medicaid and the choices of managed care plans.

An additional complication states face in reaching older persons and persons with disabilities is that most members of these groups apply for assistance with the federal government and not at state welfare offices. This complicates enrollment both by sharply decreasing the usefulness of welfare offices as a venue for enrollment activities and by reducing the access states and their contracted enrollment brokers have to information about new beneficiaries. Although states continue to use the same strategies as those discussed in Volume II to educate members of special populations (Chart E) these complications mean that members of these populations are more likely to be reached by less personalized forms of outreach such as the mail and brochures/flyers. This is also an explanation for the slightly heavier use of consumer groups in those states with managed care programs that serve the elderly or persons with disabilities.

Oregon Model

In addition to heavier use of consumer groups in the enrollment process, at least one state has responded to the problem of 'finding' those elderly and persons with disabilities who need to enroll into managed care programs through working with another state agency that is in more direct contact with these beneficiaries. In Oregon the Senior and Disabled Services Division (SDSD) is responsible for outreach, choice counseling, enrollment and eligibility determination activities for elders and people with disabilities. The state agency uses a combination of state workers and Area Agencies on Aging to perform these functions. During the initial implementation, temporary workers were added to handle the high volume of activity. The training curriculum for all staff was developed by the Oregon Medical Assistance Program (OMAP) and SDSD with consultation from health plans.

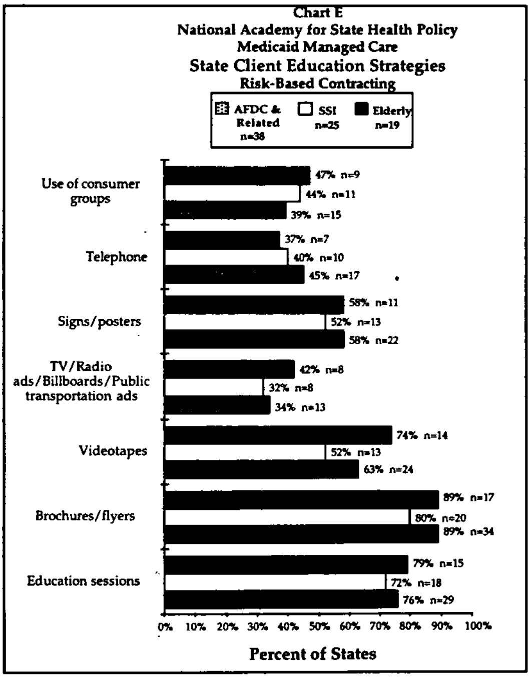


Chart E
National Academy for State Health Policy
Medicaid Managed Care
State Client Education Strategies
Risk-Based Contracting

Materials explaining the Oregon Health Plan (OHP)[27] were printed in 17 languages. Pamphlets listed primary care physicians with their plan affiliations and an indication of which physicians had sign language capacity, the bus routes for access to the physician and notations indicating whether the physician was open to existing patients, accepted or limited new members, or was fully open. Individual rather than group sessions were held to provide counseling and to enroll recipients in a plan. Area Agency of Aging (AAA) staff often mailed materials and made follow up calls to make sure the person received the materials and to respond to any questions. Plans were not allowed to conduct their own marketing nor were they allowed to work individually with AAAs or SDSD offices.

OMAP and SDSD anticipated that the counseling and enrollment process would take 1 1/2 hours per person. However, the state used more in-person interviews and fewer group sessions with elderly beneficiaries and people with disabilities and the actual enrollment time averaged 2 1/4 hours per member. The amount of time required varies with the number of plans available in each area.

All staff who have contact with beneficiaries—information and referral staff, case managers and staff involved in the intake process—receive information about the Oregon Health Plan. Oregon developed different procedures based on the status of the beneficiary. SSI beneficiaries who do not receive Medicaid long term care services contact the local Disability Services Office or Area Agency on Aging, receive information and counseling about OHP and their MCO options, and complete an enrollment form. The intake process is used to perform these functions for new applicants. Existing Medicaid Home and Community Based Services (HCBS) clients, or HCBS clients converting to Medicaid are enrolled by their case managers. Counseling and enrollment tasks add to the workload of case managers and the increased workload needs to be taken into consideration in projecting needed staffing capacity.

Medicaid beneficiaries are encouraged to select a plan on their own after receiving information on the plans, being invited to attend an orientation session or receiving face to face counseling. While case managers have the authority to "auto assign," or select a plan for recipients who have not done so within the allowable time, auto assignment has been limited. OMAP distributes a list of beneficiaries who are elderly or have disabilities and who have not selected a plan. SDSD case managers then follow up by mail or visit the beneficiary at home to assist with selection. OMAP and SDSD monitor the number of auto assignments to determine whether additional training or other intervention is needed. Incidently, those members of special populations that are dual eligibles (eligible for both Medicaid and Medicare) are only assigned for OHP covered services since case managers

---

[27] The Oregon Health Plan is Oregon's term for its Medicaid program that is made up entirely of managed care options.

cannot enroll a person in a Medicare HMO without the signature of the member or their guardian.

Through the enrollment process, beneficiaries who are receiving health or long term care services that must be continued or who will require services at the time of enrollment are identified. The SDSD case manager completes a Continuity of Care Referral which identifies service needs prior to the beneficiary's enrollment in the health plan. The form is sent to the MCO's ENCC (Exceptional Needs Care Coordinator) who then makes appropriate follow up arrangements with the beneficiary.

Other State Strategies for Enrollment

Utah uses state Medicaid workers as health program representatives to conduct education, counseling, enrollment, disenrollment and to handle complaint functions for members of special populations as well as TANF beneficiaries. The representatives are located in welfare eligibility offices. Those beneficiaries who call or visit the welfare office may view a video, receive information on each HMO and have on-line access to review the list of providers in each HMO. The enrollment staff have extended hours to make calling more convenient. In rural areas, the volume of managed care enrollment was too low to use full time, dedicated staff. In response, the Division of Health Care Financing contracted with local Health Departments to explain the fee-for-service, primary care case management and HMO options to beneficiaries. In addition to managed care enrollment, the Health Departments were contracted to work with physicians to promote the program. This arrangement was viewed as successful as evidenced by an 80% rate of voluntary selection of managed care plans by Utah's managed care eligible Medicaid beneficiaries.

In Tennessee, as in other states, Medicaid eligibility for SSI beneficiaries is determined by the Social Security Administration (SSA). SSA sends a tape to TennCare and SSI beneficiaries are randomly assigned to plans. TennCare then sends each SSI beneficiary a letter notifying the individual of the assignment and allowing 45 days to make a change. Plans assign primary care physicians for people with disabilities and elderly beneficiaries who are not dually eligible; but, do not do so for those that are dually eligible. This distinction is made because TennCare plans have limited authority over services provided to dual eligibles and the plan is responsible for providing dual eligibles only those services that are not covered by Medicare.

Dual Eligibility and Enrollment

States that enroll elderly beneficiaries and people with disabilities into Medicaid managed care programs must also address dual eligibility—at least to decide if they will exempt dual eligibles from program participation or will find ways of accommodating the complications dual eligibility brings to Medicaid managed care.

As of June 30, 1996, only four of the 16 states that enroll persons with disabilities and seven of the states that enroll older persons enrolled dual eligibles into their programs.[28] Since that time several other states have begun to enroll dual eligibles, but the over-all number of programs that enroll dual eligibles remains small.

Nonetheless, states are intensely interested in enrolling dual eligibles into managed care due to the large number of members of special populations that are dually eligible and the high cost of caring for this subgroup. While state specific figures are not available, six million Medicare beneficiaries also participate in state Medicaid programs. Estimates suggest that 95-98% of the elderly Medicaid beneficiaries and 50% of the people with disabilities are covered by Medicare.

Medicaid managed care programs that enroll dual eligibles need to develop enrollment procedures that take into consideration the options available under Medicare, especially in states with a sizeable Medicare HMO market penetration. In July 1997, 4.8 million Medicare beneficiaries had enrolled in HMOs.[29] While enrollment has been increasing over 30% a year, the provisions of Title IV-A of the Balanced Budget Act of 1997 is likely to expand enrollment even further. This new law will allow Medicare to contract with Provider Sponsored Organizations and Preferred Provider Organizations in addition to HMOs. Each year beneficiaries will voluntary select a delivery system during an open enrollment period. Beneficiaries may choose from fee-for-service, HMOs, PPOs and PSOs. Beginning in 2002, once a beneficiary selects an option, they will remain in that system for the full calendar year. Beneficiaries may change their selection once during an annual 90 day open enrollment period. This law is expected to expand the number of managed care options available and to simplify enrolling dually eligible beneficiaries in managed care programs. Also, importantly for Medicaid agencies, similar changes to Medicaid enrollment rules (12 month lock-in with a 90 day open enrollment) have potential to bring the administrative rules of these two programs closer together.

Medicaid and Medicare have separate enrollment procedures that need to be coordinated in order to establish the same effective enrollment date when a beneficiary enrolls in one plan for both programs. The enrollment process for dual eligibles in most states is complicated by the procedures and timetables followed by Medicare and Medicaid. Medicaid recipients cannot be enrolled prospectively and

---

[28] Please see Volume I for more details about specific state policies. It is likely that many of the state programs that enroll dually eligible older persons are PACE programs specifically designed to serve dually eligible frail older persons. These programs operate under special federal waivers that reduce the administrative problems created by dual eligibility.

[29] The number of dually eligible beneficiaries enroll in Medicare HMOs is not known.

Medicare members are not typically enrolled retroactively.[30] As a result, recipients who enroll in a plan for both Medicare and Medicaid are enrolled immediately for Medicaid and the plan bills Medicare fee-for-service until the Medicare process is completed, typically 30-60 days.

State Experience Enrolling Dual Eligibles

States that enroll dual eligibles have put different levels of effort into tracking the Medicare enrollment decisions of dually eligible beneficiaries in order to coordinate enrollment in Medicaid managed care program and the benefits available under each program. Minnesota's Senior Health Options has had the most success in coordinating the two programs. This program's waiver combines the Medicaid and Medicare enrollment systems. County offices may complete the single enrollment form. The form is submitted to the state Medicaid agency, verified and submitted to HCFA. The streamlined process means that the enrollee only has to sign one form and allows enrollment to be effective in the following month if the completed form is submitted to HCFA six days prior to the end of the preceding month.

As previously mentioned, Oregon also places great importance on making every effort to ensure that an individual that chooses a plan for Medicare services is enrolled into that plan for Medicaid services. Of course, since Medicare freedom-of-choice takes precedence over Medicaid's mandatory enrollment the choices are complex and vary with the beneficiary's preference for receiving Medicare benefits. The various choices and their effect on enrollment are identified below.

- If the beneficiary is already enrolled in a Medicare HMO at the time of Medicaid enrollment, the beneficiary may either:
  - enroll in the plan for Medicaid services if the HMO is also an Oregon Health Plan (OHP) contractor; or
  - remain in the HMO for Medicare benefits and receive Medicaid services on a fee-for-service basis if the HMO is not an OHP contractor or if the HMO membership is a private, premium-based policy which the member wishes to retain.
- If the beneficiary is not currently enrolled in a Medicare HMO, but chooses an OHP plan that is also a Medicare HMO, that beneficiary will be enrolled in that HMO Medicaid *and* Medicare plans.
- If the beneficiary chooses an OHP plan that does not offer a Medicare HMO, the beneficiary is enrolled in the OHP plan for Medicaid services

---

[30] HCFA has indicated that retroactive Medicare enrollment will be considered.

and Medicare is billed fee-for-service for Medicare services. Cost sharing for out-of-network services is not covered.

Other states have responded to the need for coordination by limiting their programs to allow dual eligibles to retain freedom of choice to receive Medicare benefits from any certified provider. For example, Tennessee enrolls dually eligible beneficiaries in plans only for services that are not covered by Medicare. In this State, the TennCare Bureau notifies plans as new members enroll and identifies new members who have Medicare coverage. Medicaid-only members receive a member handbook and membership card. However, as previously discussed, dually eligible beneficiaries are not required to use network providers and do not receive member handbooks. Instead, they receive membership cards and materials explaining how to access their pharmacy benefits and other benefits that are not covered by Medicare.

Tracking Enrollment of Dually Eligible Beneficiaries

In order to coordinate Medicaid enrollment decisions with Medicare, state enrollment systems must be able to identify beneficiaries that have enrolled in a Medicare HMO. A number of states receive regular information from HCFA or health plans themselves to track Medicare HMO enrollment. Arizona, California, Florida, Kentucky, Louisiana, Massachusetts and Texas indicated that tapes are now being received from HCFA. A memorandum of agreement is pending between HCFA and Maryland to share enrollment information. Ohio has requested on-line access to the information. Alabama and Illinois receive monthly lists from the Medicare HMOs. Generally, most states have not requested these tapes, or are not aware that HCFA will make them available.

Disenrollment

Critics of managed care are concerned that financial incentives to enroll healthy members (biased selection) may lead to disenrollment of members who are hard to serve and have high utilization patterns. Given the wide variation in costs between individual members of special populations this concern becomes even more acute in those programs that serve the elderly and persons with disabilities.

Partially in response to this concern, Medicaid agencies in Arizona and Oregon approve all disenrollments to ensure that plans are not encouraging difficult to serve or costly members to leave the plan. In these two states, state staff track disenrollment rates as a quality improvement measure and to determine whether disenrollment is voluntary or whether plans may be forcing people with high utilization or complex needs out of their plan. Most disenrollments in Oregon have been members with substance abuse conditions who are noncompliant. Health plans send documentation to OMAP concerning what services and interventions were planned and how they were implemented. State officials may consult with the plan and recommend further interventions before disenrollment is approved.

Regence HMO Oregon staff noted that very few cases produced disagreements that could not be resolved. A number of interventions are attempted before plans request that a member be disenrolled.

Dually eligible elderly beneficiaries and people with disabilities are treated differently in Oregon because disenrollment must be coordinated with Medicare. OMAP and SDSD have devised a Medicare Health Plan Disenrollment Form to facilitate changing of plans by dual eligibles. Case managers send the form to the HMO from which the member plans to terminate coverage prior to the end of the month in which enrollment ends. A copy is also sent to the new plan to alert them to the pending disenrollment from the other plan. Since HCFA's current system cannot process two transactions simultaneously, the first HMO submits a termination report to HCFA and the new plan holds the application and submits it to HCFA the following month. Medicaid enrollment takes effect in the subsequent month but Medicare enrollment is not effective for 60-90 days. This process has worked as long as disenrollment forms are filed. In many instances, the case manager is either not involved in the Medicare disenrollment, or fails to send the form. These gaps delay disenrollment. To simplify this cumbersome process, HCFA approved a process which allows processing of termination of members using the OMAP monthly transmittal.

Highlights

- States can establish an enrollment process that enables them to collect information about care the enrollee is receiving at the time of enrollment and convey that information to the new plan.

- The federal government's role in eligibility determination for the elderly and other beneficiaries of the SSI program reduces the usefulness of the welfare office as a venue for enrolling members of these populations. This means that members of these populations are less likely to be informed in face-to-face interviews and more likely to find out about managed care options through the mail or over the telephone.

- Medicaid agencies can effectively coordinate with other state agencies that are in more routine contact with members of special populations to better inform beneficiaries about their managed care options.

- Informing beneficiaries who are older or have a disability can take a significant amount of time. Oregon reported spending more than 2 hours per member.

- Striking a balance between steering beneficiaries to an appropriate plan versus inappropriate steering can be difficult. Plans with experience with populations who are high utilizers may experience adverse selection. An effective risk adjustment mechanism may neutralize adverse selection.

- The different managed care options that Medicare beneficiaries have can complicate the Medicaid enrollment process for dual eligibles.

Financing Managed Care for Vulnerable Populations

There are several aspects of finance that states should consider re-examining when developing programs that serve the elderly or persons with disabilities.

- States considering contracting with community based organizations may wish to re-examine their solvency requirements, since these providers may be unable to establish the same level of risk-reserves as a commercial HMO.

- States generally vary their capitation payments based on demographics such as geography, sex, and age. These states may wish to re-examine these policies as some studies have shown that these are not the factors that account for the greatest amount of variation in cost among members of special populations.

- States may wish to re-examine their risk-sharing arrangements with plans, since the potential for selection bias and rapid changes in the means of treating some subpopulations may make projecting average costs more of a 'best guess' than an 'accurate projection.'

Solvency Requirements

Solvency requirements are the financial requirements plans must meet in order to participate in the Medicaid managed care program. In those states that contract only with HMOs that are commercially licensed to operate in the state, the Insurance agency typically ensures that the plan has sufficient reserves, maintains an acceptable medical loss ratio, etc. Indeed of the 36 state Insurance agencies that responded to a 1996 survey, only three did not report regulating the financial aspects of managed care organizations.[31] This allows the Medicaid agency to focus its oversight efforts on other aspects of plan performance.

Some states that operate managed care programs for special populations have decided to contract with non-commercially licensed organizations, usually

---

[31] Jane Horvath and Kimberly Irvin Snow, *Emerging Challenges in State Regulation of Managed Care: Report on a Survey of Agency Regulation of Prepaid Managed Care Entities*, (Portland, ME: The National Academy for State Health Policy, 1996), pp. 11-14.

community based organizations that have experience serving these populations. Unfortunately these organizations are frequently unable to meet the financial standards of commercial HMOs—the reserve requirements alone may exceed some community based organizations' entire annual budget. Nonetheless, some states, such as Wisconsin, have decided to contract with these agencies for a number of reasons, including:

- these organizations experience may give them the tools they need to better manage enrollee care and produce cost savings; and
- these organizations are familiar to members of these populations and their advocates. This may reduce these groups concerns about entering managed care.

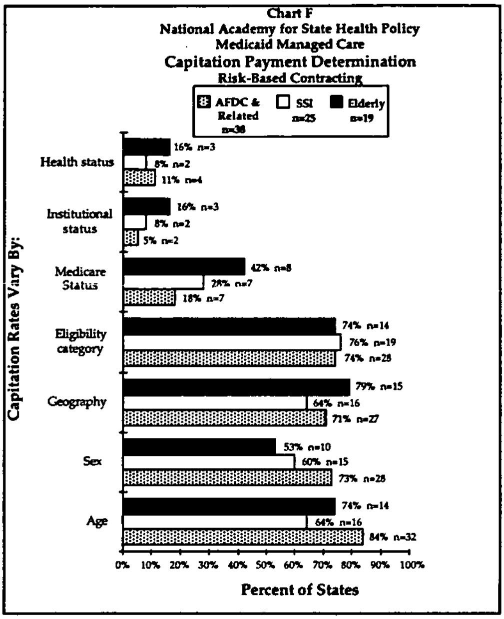
In these cases the Insurance agency will not regulate the contractor's finances and the Medicaid agency must step into this gap. (Federal regulations require Medicaid agencies to examine the solvency of all managed care contractors.) In some states this may mean setting financial standards for the first time or modifying the current standards if they were identical to the Insurance agency's standards. It may also mean learning new oversight skills if the Medicaid agency has not examined contractor finance in the past. Of course, the level of scrutiny (and financial reserves) will vary with the amount of risk the Medicaid agency intends to pass on to the contracted plan. For example, if the agency intends to pass on very little risk to the entity that state may simply wish to consider estimating the maximum amount the plan will need to contribute to any financial loss and ensure that the plan has that amount in reserve.

Capitation Payments

Due to the extreme variation in the cost of caring for individual members of special populations states may wish to consider not paying one fee for all SSI enrollees or all aged enrollees. Instead states should consider paying several different rates for members of these groups or paying one rate that varies from plan to plan depending on the characteristics of those beneficiaries who chose to enroll into each plan. For example a plan that enrolled more beneficiaries with active AIDS may be paid a higher payment than other plans.

Some states already vary their payments based on enrollee characteristics. For example, Minnesota pays plans a number of different rates based on factors such as the individual's age, sex, Medicare status, and institutional status. While, Colorado pays each individual plan a single different capitation rate adjusted based on the demographics of the population enrolled in that plan. As shown by Chart F[32] most states do adjust the rate based on enrollee characteristics.

Unfortunately, the characteristics most states use do not account for most of the variation in costs among populations that are elderly or have a disability.[33] In these cases the cost of caring for an individual is more likely to vary by diagnosis, institutional status, or ability to perform activities of daily living. Since the object of adjusting capitation rates is to bring total payment in line with the cost of caring for enrolled individuals it will be important for states to continue to find ways to adjust rates based on these more significant factors.



This may mean significant changes to state systems that are not designed to capture this information—much less make payments based on these factors. Even collecting some of this information may be difficult as most states do not have access to the federally maintained information about disabling conditions for persons with disabilities and the systems that determine eligibility for nursing home placement are almost always outside the Medicaid agency. Some states such as Massachusetts and Maine are beginning to deal with these issues but much work remains to be done.

---

[32] Charts F and G are based on state reported information and reflect program status as of June 30, 1996. For more information about an individual state's policies please refer to Volume I.

[33] Richard Kronick, Zhiyuan Zhou, and Tony Dreyfus, "Making Risk Adjustment Work for Everyone," *Inquiry* 32 (Spring, 1995), 41-55.

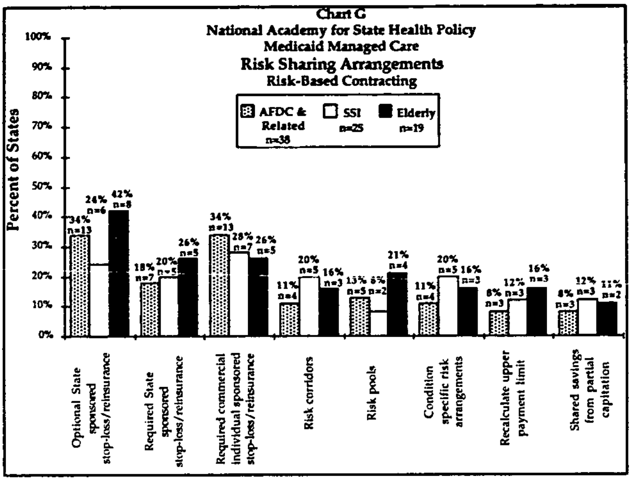
Although technical advice for calculating and adjusting rates based on these new factors is beyond the scope of this publication there are a number of publications available to those interested in these subjects. Three of particular interest are:

- Richard Kronick and Tony Dreyfus, *The Challenge of Risk Adjustment for People with Disabilities: Health Based Payment for Medicaid Programs,* (Princeton, NJ: The Center for Health Care Strategies, 1997).
- Tony Dreyfus, *Using Payment to Promote Better Medicaid Managed Care for People with AIDS* , (Washington DC: The Henry J. Kaiser Family Foundation, 1997). This publication was produced for The Kaiser Family Foundation Workgroup on Medicaid for Persons with AIDS, which was convened by The National Academy for State Health Policy.
- Issues specific to financing and payment for dual eligibles are discussed in The National Academy for State Health Policy's publication, *Integration of Acute and Long Term Care,* due to be released in early September, 1997.

Sharing Risk

States may wish to consider sharing risk with plans that serve special populations. As previously discussed, there is significant variation in cost among members of special populations. Until states implement and test systems for calculating and varying payment rates that better accommodate the wide variation in cost they may wish to share risk with plans. This could help ensure that neither the plans nor the state are harmed financially during the implementation of Medicaid managed care for elderly persons or persons with disabilities. This will in turn help reassure beneficiaries and their advocates that plans will not inappropriately deny care due to insufficient funds to cover the cost of care.

Even after states develop rate payment methods that work for persons with disabilities and the elderly, some states may want to consider continuing to share risk with contractors for some subpopulations. For example, the accepted treatment protocols for treating persons with HIV has changed rapidly in the past. Sharing risk is one way of providing protection to plans concerned that changing treatments may create significant increases in the cost of caring for some subgroups. Some models of risk-sharing, such as risk-corridors, may also provide states an opportunity to recoup any excessive profits plans could make if changes in technology actually lowered the over-all cost of caring for Medicaid beneficiaries.



As shown in Chart G stop loss/reinsurance is the most popular form of risk-sharing among states with managed care programs. Under this form of risk-sharing the plan is usually responsible for an individual enrollee's care until total costs for that individual exceed a pre-determined threshold ($50,000 for example) after that point the entity sponsoring the stop loss becomes responsible for the cost of caring for the individual. This form of risk-sharing protects the contractor from excessive loss, but does not provide the State any means of recouping excessive profit (if the state wishes to do so).

The next most popular strategies are risk corridors and risk pools. These methods of sharing risk depend more on aggregate experience than individual experience. In other words, they share overall program financial risk between the state and the plan or among plans. Specifically, risk corridors are a means of protecting both the plan and the state from financial risk on an aggregate basis. At is simplest, this approach could consist of the plan and the state agreeing to split any loss or profit that exceeds 25% of revenue from capitation payments for Medicaid beneficiaries on a fifty/fifty basis. In order to create appropriate incentives most states that use this approach have multiple corridors that entail sharing profit and loss in different proportions depending on the amount of profit or loss. Several states such as Wisconsin and Ohio use this approach in their programs designed to serve persons with disability.

Risk pools are usually used to provide plans with protection against adverse selection relative to other contractors. In other words, to share financial risk among all plans. Oregon, for example, uses this approach to accommodate for an unequal distribution of pregnant women (and the resulting cost of delivery) in health plans. This State retains a small portion of each capitation payment made to plans during the year. This retained money becomes the 'pool'. At the end of the year the State determines the number of births to Medicaid beneficiaries that each plan paid for. Then the state distributes the money in the 'pool' to plans in proportion to the percent of total Medicaid births each plan paid for. This strategy could be used for other easily measurable conditions, such as the number of plan members who receive protease inhibitors.

Highlights

- States may wish to change their capitation payment systems to pay those plans that serve more expensive populations more.
- Methods for adjusting payments based on diagnosis or ability to perform the activities of daily living are just being developed and states will need to make extensive changes to their payment processing system to accommodate these new systems.
- States should consider how to best set financial solvency standards and monitor contractor compliance with these standards. Particularly if the state is contracting with plan that does not have a commercial license.
- Risk-sharing can not only protect contractors from excessive losses, but may enable states to recoup excessive profits.

Quality Improvement

In general state Medicaid agencies cite improving the quality of care provided to enrollees as one of the most important reasons for moving Medicaid beneficiaries into managed care. As reported in previous volumes, some states (e.g., Rhode Island) have measured improvements in the quality of care and health outcomes produced by managed care for AFDC (TANF) beneficiaries. In large part, states attribute these improvements, to the activities they undertake to make sure that individual health plans and the program as a whole provide access to quality care.[34]

---

[34] Several other publications from the National Academy of State Health Policy also address the issue of ensuring quality in Medicaid managed care programs. The publication most pertinent to programs that serve members of special populations is: Maureen Booth, *Look Before You Leap: Assuring the Quality of Care of Managed Care Programs Serving Older Persons and Persons with Disabilities*, (Portland, ME: The National Academy for State Health Policy, 1996).

Those states that use managed care to serve persons with disabilities and the elderly believe that, with proper oversight, managed care can also produce improvements in the care delivered to these special populations. Of course, since almost all of these programs are new, they have not yet proven their ability to improve the health status of these groups of Medicaid beneficiaries.[35]

As described in Volume II of this **Guide**, state oversight activities include developing standards for health plan performance, measuring plan performance, and working with plans to improve performance. States use this same approach to overseeing contractors that serve Medicaid beneficiaries who are elderly or have a disability. However, state staff report that they modify this generic system to better accommodate the needs of persons with disabilities and the elderly by developing measures for aspects of health plan performance that are more pertinent to special populations. For example, in a program serving AFDC (TANF) beneficiaries measuring plan performance in providing childhood immunizations is extremely important. But, for persons with AIDS developing standards and measures for the use of protease inhibitors (as Massachusetts has done) is a more pertinent measure.

Earlier sections of this chapter discussed standards and structures in areas of particular concern to programs serving elderly beneficiaries or those who have a disability (e.g., access and care coordination) and the means for measuring plan performance is unchanged from those described in Volume II. Therefore, the bulk of this chapter will focus on those aspects of plan performance that are formally identified as part of a quality improvement system—the standards states require a plan's internal quality program to meet and the external reviews states conduct. (This discussion assumes the readers familiarity with HCFA's Quality Assurance Reform Initiative (QARI) guidelines, which contain guidelines for both of the aspects of quality assurance/improvement discussed here.) Finally, since many members of special populations are dually eligible,[36] this section will discuss the impact that Medicare has on Medicaid quality assurance activities and some efforts underway to bring the two systems closer together.

---

[35] For more information on quality assurance for special populations please refer to: Maureen Booth, *Look Before You Leap: Assuring the Quality of Care of Managed Care Programs Serving Older Persons and Persons with Disabilities*, (Portland, ME: National Academy for State Health Policy, 1996).

[36] Dual Eligibles are beneficiaries who are served by both the Medicaid and the Medicare programs.

Internal Quality Program Standards

Internal quality program standards refer to the standards that states require each plan's quality assurance/improvement program to meet.[37] Ensuring that plan internal systems work to ensure the delivery of quality care is an important first step in ensuring that the overall program delivers quality care. In general, states require plans to establish a committee to oversee all plan activity, including establishing standards for participating providers, identifying issues for study, conducting studies, and developing the plan's response to study findings. Most states specify some aspects of the committee's structure, some of the sources of information the committee must use to identify study topics and may sometimes even identify a specific study topic. Although most states include specifications for the same types of issues, some states that enroll special populations into Medicaid managed care plans have modified their specific requirements to better accommodate the health care needs of these populations. As demonstrated by Chart H, in 1996 many states based these standards either on NCQA's standards or the previously discussed QARI guidelines.

Oregon, for example, includes several provisions in its administrative code to ensure that each plan's internal quality assurance system will meet the needs of the elderly and persons with disabilities. Specifically, this State specifies that the membership of the quality assurance committee shall include or have access to consultation from individuals with knowledge of all populations served including those who are elderly or who have a disability. In addition, Oregon specifies that several of the reviews[38] each plan is required to perform must address the needs of plan members who are elderly or

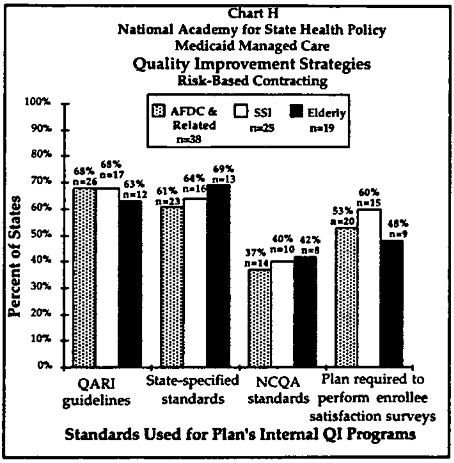


Chart H
National Academy for State Health Policy
Medicaid Managed Care
Quality Improvement Strategies
Risk-Based Contracting

---

[37] Under the Balanced Budget Act of 1997, HCFA will develop quality assurance standards for use by states in preparing a quality assessment or improvement strategy. Internal quality program standards must be at least as extensive as those imposed by HCFA.

[38] Areas that plans must review include: an annual review of the plan's entire quality assurance program, utilization of services and its relationship to adverse or unexpected outcomes, and review of member educational programs.

who have a disability. Finally, this State specifies that the committee must review and analyze all complaints on a quarterly basis, "including review of persistent and significant complaints from OMAP members (or their representatives) who are Aged, Blind, Disabled or Children Receiving SOSCF or OYA Services."

Many other states take an approach similar to Tennessee's. This State seeks to ensure that the plan's quality assurance program is comprehensive for *all* Medicaid beneficiaries enrolled in the plan. Specifically, the Tennessee contract states that these activities must "review the entire range of care provided by the organization, by assuring that all demographic groups, care settings, and types of services are included in the scope of the review." Tennessee's contract goes on to further specify that for the clinical studies the plan must perform, "...reflects the population served by the managed care organization in terms of age groups, disease categories, and special risk status." Finally, continuing this theme Tennessee specifies that the plan must develop clinical guidelines for the "full spectrum of populations enrolled in the plan."

External Reviews

In addition to standards for a plan's internal quality assurance/improvement system, states perform their own studies to directly examine the care provided to Medicaid enrollees. Federal regulations require that states hire an external quality review organization (EQRO) to review the care provided by comprehensive health plans on an annual basis. In addition many states undertake their own studies to directly examine some aspects of the care delivered by plans. These studies were discussed in detail in the last chapter of Volume II, so that discussion will not be repeated here. Rather this section discusses some of the studies two states that have programs that serve special populations (Oregon and Arizona) are undertaking.

State Experience with EQRO Reviews

Under Medicaid, the state agency must contract with a peer review organization (PRO), a PRO-like entity or an accreditation agency to evaluate the quality of care within reach plan serving Medicaid beneficiaries. There are no federal prescriptions for the scope of work conducted under the external quality review function for Medicaid, and, over time, states have broadened this activity to include focused studies, random record reviews, assessments of a plan's internal quality management program and member surveys.[39]

In Oregon the EQRO contract is overseen by the Research and Analysis team within the State's quality assurance unit. This team also reviews plan solvency, reviews

---

[39] The Balanced Budget Act of 1997 expands the types of entities that are qualified to conduct the external independent review of managed care plans. Also, HCFA, in coordination with the National Governors' Association and The National Committee for Quality Assurance, will develop the protocols for the external quality review function.

enrollee utilization patterns, and conducts surveys. This team selects areas for EQRO review based on information gathered from the other activities it manages and from data collected by the State Ombudsman Office.[40] The EQRO function in Oregon has four main components: quality studies including focused studies on diabetes and adult depression, encounter data analysis, delivery of selected preventive services (mammograms, pap smears, immunizations, diabetes) and statewide focus studies of identified issues such as emergency room use. The encounter data review looks at 39 performance measures. For the elderly and persons with disabilities, the reviews examine access to specialists and durable medical equipment.

Arizona made diabetes management a priority for clinical studies. This State will focus on children and adults as well as the elderly in its study. The state's EQRO study will develop baseline information that can be used to measure improvements over time.

Reviews Performed by State Staff

These reviews are not required by federal regulations, but many states perform these studies at their own initiative.[41] These are usually performed to examine an area of particular concern with program performance. As discussed in Volume II states use a number of sources of information to identify potential topics for these studies, such as, utilization reports from plans, complaint and grievance information, information from advocates and providers, and health outcomes (after the program has operated long enough for it to produce any such outcomes). These studies may focus on one or two plans that have been identified as experiencing a particular problem, but most often these reviews examine the provision of care by all plans participating in the managed care program.

Oregon

Oregon staff has performed or is performing three reviews.

- An evaluation of the Exceptional Needs Care Coordination (ENCC) program was completed in the fall of 1996. This review assessed whether the program was meeting the needs of the population eligible for ENCC services (elderly, persons with disability and children in foster care) as intended by the legislature, to gather information about innovative use of the position and to

---

[40] For more information on Ombudsman programs please refer to: Jane Horvath and Neva Kaye, *Snapshot of Medicaid Managed Care Ombudsman and Grievance Procedures*, (Portland, ME: The National Academy for State Health Policy, 1997).

[41] The Balanced Budget Act of 1997 requires states to develop a quality assessment and improvement strategy and to conduct periodic regular examinations of the scope and content of the strategy. This would include monitoring and evaluating the quality and appropriateness of care.

assess compliance with minimum standards. The final report of this evaluation is being prepared.

- A review of plan quality improvement systems will be completed this year. This review will examine all aspects of the quality improvement system, including those specifically focussed on members of special populations that were described earlier in this section.

- A review of plan systems for compliance with State requirements regarding complaints, client rights and due process was also recently completed. This review examined a number of factors that include access to interpreters, availability of appropriate information in multiple languages, access under American with Disabilities Act (ADA) rules, ability to meet the needs of visually impaired members, written procedures for accepting, processing and resolving complaints, a system for documenting complaints, option for consumers to use the plan's internal process or to appeal directly to Medicaid, and a procedure for reviewing and analyzing complaints.

Arizona

Arizona has implemented a clinical quality indicator project for elderly and physically disabled beneficiaries. The indicators include immunizations, pressure ulcers, use of psychotherapeutics, hospitalization and emergency room utilization, activities of daily living (ADL) and fracture-related falls. Depending in the indicator, data is collected through on-site chart reviews, encounter data and assessment forms. The ADL indicator measures whether ADL scores have improved, remained the same or declined since the previous assessment. Hospital and emergency room (ER) use data will be collected for:

- the number of ER visits;
- percentage of members with ER visits;
- ratio of ER visits to number of members with visits;
- percentage resulting in hospitalization;
- number of hospital admissions;
- percentage of members admitted during a year;
- ratio of hospitalizations to the number of members who have had admissions;
- average length of stay; and
- the five most frequent diagnosis.

The data collected for each indicator will be used to develop baseline measures from which later performance standards will be developed.

A focus study of members in nursing homes and community settings with pressure sores was completed and a report was issued in February 1997. The report found that the overall prevalence of pressure ulcers was 4.47% but was greater for nursing home residents (5.67%) than for members in home and community based settings (2.39). The report analyzed data by age, gender, race, classification and treatment modality. This descriptive study did not make recommendations. The report will be reviewed by the quality assurance committee in each contractor.

In 1995, Arizona began to consider using encounter data to measure quality. Indicators for chronic illness and other areas were developed in conjunction with the plans. The overall approach to quality uses encounter data to identify which members received what services. Clinical studies will be used to determine timely detection, follow up and treatment. Encounter data is used to set benchmarks. State and plan staff indicated that encounter data is not always a reliable measure of utilization. For example, immunizations can be received in a number of settings which are not always reported to the health plan.

Arizona also operates a managed care program designed to serve those Medicaid beneficiaries in long term care. This program called ALTCS (Arizona Long Term Care System) provides all Medicaid services to beneficiaries who are eligible for long term care services. The state conducts annual reviews of these contractors and makes their findings public. State staff review a random sample of up to 1,000 member records to determine compliance with ALTCS policies (e.g., case management requirements, appropriateness of services, were the services delivered). In addition, a random sample of 30% of the ALTCS members are contacted to determine whether their understanding of the services they are supposed to receive, whether the services are being received, and their level of satisfaction.

Quality Assurance for Special Populations and Dual Eligibility

As previously discussed many members of special populations are dual eligibles (eligible for both Medicaid and Medicare). Those Medicaid agencies that enroll dual eligibles into health plans should be aware of some special circumstances and issues they may encounter.

First, it may be difficult to measure some key aspects of the care delivered by health plans to dual eligible enrollees because neither Medicaid nor Medicare have complete information about the services delivered to dual eligibles. In most states plans and fee-for-service providers report services provided to the agency that pays for the service. This means that Medicare has most information about acute care and that Medicaid has most information about the long term care provided to dual eligibles.

Some states are working with HCFA to find a means to resolve this situation. To date, Minnesota is the only state that receives information from health plans about both the Medicaid and Medicare services provided to plan enrollees. This State attained this ability through use of an 1115 waiver that identifies the State as HCFA's agent for the Medicare program, at least for those Medicaid beneficiaries that enroll in this program. Some other states (e.g., Maine and Massachusetts) are working with HCFA to obtain and analyze information about fee-for-service claims paid for Medicaid beneficiaries.

An overarching issue that directly relates to plans that contract with both Medicaid and Medicare to serve dual eligibles is that these plans have to meet both Medicare and Medicaid requirements for quality assurance. Although there are many similarities between the two sets of requirements they are not identical and plans may be frustrated by having to deal with multiple 'government' regulations and entities. Also, given that both agencies are attempting to ensure quality this could become a singular opportunity for both the State and federal government to maximize resources by combining (or at least avoiding duplication of) their oversight activities.

Medicare Quality Standards

This section describes Medicare quality standards in order to provide Medicaid agencies with information they may need if they enroll dual eligibles into Medicaid managed care plans. HCFA's quality standards for Medicare HMOs are contained in the requirements for approving risk contracts and are consistent with many Medicaid contract requirements. Examples of Medicare requirements include: plans must demonstrate the adequacy of their network; make arrangements for after hours care; implement monitoring systems to evaluate waiting times for appointments for routine scheduled and urgent care, member complaint procedures, inappropriate use of emergency rooms, the number of requests to change primary care physicians and the volume of out of plan referrals by specialty and service; and plans must ensure continuity of care among health care providers.[42]

HCFA's protocol reviews the HMO's written program for continuous quality improvement which includes emphasis on health outcomes, peer review, systematic data collection and steps for remedial action. In addition, the quality assurance program must include a process for determining whether problems exist and for evaluating the implementation of corrective action. Health outcomes must be examined by focusing on diagnoses or procedures which are prevalent in the plan, and the effectiveness of mechanisms designed to influence the behavior of physicians. Peer review committees are required. The data collection system must collect performance data, patient results and interpret the results to clinicians.

---

[42] , The Balanced Budget Act of 1997 defines the elements of a Medicare risk contractor's quality assurance program. Greater emphasis is placed on health outcomes and the dissemination of information on quality and outcome measures "to facilitate beneficiary comparison and choice of health care coverage option."

HMOs with risk contracts must have an agreement with a Peer Review Organization. Beginning in 1997 HCFA required that Medicare HMOs begin submitting HEDIS 3.0 data which is also required by some state Medicaid programs.

Finally, the external quality review conducted for Medicare by Peer Review Organizations, follows a prescribed scope of work which is revised periodically. The current scope of work includes focused pattern of care studies in the areas of improving the care of beneficiaries with acute myocardial infarctions or diabetes and preventive health care, including mammography services and flu vaccines.[43]

Potential for Coordination Between Medicaid and Medicare

Since the goal of both programs is to provide access to quality care for their beneficiaries and many of the requirements are very similar there is potential for coordination between the two agencies. For example, Oregon is holding discussions with the HCFA regional office about combining the PRO and EQRO functions. Though each program has its own philosophy, practices and goals, there is an interest in collaborating where possible. State officials supported a previous recommendation by the Institute of Medicine which proposed developing regional quality improvement organizations to develop Medicare, Medicaid and private sector collaboration. Also, one of the current priorities for Medicare is diabetes management. Arizona has also made diabetes management a priority for clinical studies, yet it will focus on children and adults as well as the elderly in its study.

Finally, an emerging project may help states address overlapping responsibilities for dual eligibles in managed care. HCFA has contracted with the National Academy for State Health Policy to revise the QARI guidelines and, to the extent feasible within current regulatory authority, develop a common set of quality management standards for Medicaid and Medicare. This initiative, known as the Quality Improvement System for Managed Care or QISMC, will result in the development of a common approach to quality management and improvement, standards, and reviewer guidelines to evaluate compliance with the standards. Public review documents will be available in the Fall of 1997 with final approval expected in June 1998.

The QISMC initiative blends the strengths of each program. Through use of the QARI guidelines, Medicaid agencies have historically been quite definitive about their expectations on how plans should conduct their internal quality management programs. While the standards themselves have been explicit, few states have had

---

[43] The Balanced Budget Act of 1997 promotes coordination between the external quality review s conducted under the Medicaid and Medicare programs. States are encouraged not to duplicate review activities conducted as part of the Medicare external review and, at the option of the state, to exempt certain Medicare risk contractors who would otherwise be subject to an external quality review under Medicaid.

review systems in place to determine whether in fact the quality management systems have been properly implemented and if they are effective. Medicare, on the other hand, has had fairly broad and rudimentary requirements but an operational review process to determine whether a plan's program is functioning effectively.

The following products will be prepared:

- a conceptual framework to guide the design and maintenance of an effective quality monitoring system for Medicare and Medicaid;
- joint set of internal quality management program standards for both programs based on existing federal standards and those used by private accrediting bodies;
- reviewer guidelines to assist HCFA and state Medicaid agencies in monitoring compliance with proposed standards; and
- an implementation strategy.

Highlights

- States modify the approaches they use to assure quality of care for all population enrolled in managed care primarily by developing measures of plan performance that are more pertinent to the elderly and persons with disabilities.
- States that use managed care to serve beneficiaries who are members of special populations may either specifically identify that the needs of these specific groups must be incorporated into plan quality assurance/improvement activities or specify that these activities must address the needs of all groups enrolled in the plan.
- Consumer satisfaction surveys and complaints provide valuable sources of information to identify potential quality problems. Particularly in new systems of care that have not been operating long enough to produce changes in health status or outcomes.
- In order to assess the quality of care provided to dual eligibles Medicaid and Medicare will need to share information about the services each agency pays for.

Summary

As Medicaid agencies continue to enroll older persons and persons with disabilities into managed care they will need to accommodate the special needs of these populations. States will need to examine and perhaps modify the means they use to: assure access, enroll beneficiaries, require plans to do care coordination, and assure quality. States will also need to consider the best means to deliver the long term care services that many members of these populations need and coordinate with the Medicare program that also serves many members of these populations.

Chapter Three

Medicaid Managed Care and Mental Health

Trish Riley
Joanne Rawlings-Sekunda
Cynthia Pernice

August
1997

NATIONAL ACADEMY
for STATE HEALTH POLICY

Additional funding for this chapter provided by
The Henry J. Kaiser Family Foundation and The Health Care Financing Administration
through a contract with Research Triangle Institute

Chapter 3
Medicaid Managed Care and Mental Health[1]

Introduction

The Henry J. Kaiser Family Foundation and the federal Health Care Financing Administration (HCFA), have launched a state symposia series, in which small groups of state officials explore critical issues in building Medicaid managed care programs. The second symposium, "Transitioning to Managed Care: Medicaid Managed Care in Mental Health," was held April 24, 1997 in Washington, D.C. Nine states participated: Colorado, Connecticut, Delaware, Iowa, Massachusetts, Oregon, Tennessee, Washington, and Wisconsin. They were selected due to their diverse approaches to Medicaid managed mental health care. All currently enroll Medicaid beneficiaries. (Note: This chapter does not provide a detailed explanation of individual state approaches to managed mental health care but presents the lessons these states have gleaned from their work. Appendix L provides a brief description of each state's approach. Appendix M contains charts summarizing these states' initiatives.)

The symposium and this paper limit discussion to mental health, not the full range of behavioral health. This was done only as a means to organize complex information and allow a substantive one-day discussion, about which this paper reports.

Integrating Physical and Mental Health Care: To Carve Out or Not to Carve Out?

System Design

States have developed a variety of approaches to Medicaid managed mental health care, which continue to evolve as their experience grows. While no state approach

---

[1] This chapter is a shortened version of: Trish Riley, Joanne Rawlings-Sekunda, and Cynthia Pernice, *Transitioning to Managed Care: Medicaid Managed Care in Mental Health*, (Portland, ME: National Academy for State Health Policy, 1997). This publication is the second in The Kaiser-HCFA State Symposia Series produced by the National Academy for State Health Policy under a contract with Research Triangle Institute.

is a pure 'model,' for purposes of the discussion, we identify the following models.

- *Integrated model:* in which mental health services are included in the general physical managed care program.[2]
- *Partial carve-out model:* in which some mental health services are integrated, but other mental health services and/or populations operate under a separate managed care program.[2]
- *Full carve-out:* in which mental health services and/or populations are completely separated from the physical health program into their own managed care program.[2]

States choose specific models for a number of reasons.

- *Integrated model:* Four of the states participating in the symposium treat managed mental health care as a "carve-in": Connecticut, Massachusetts (HMO program), Oregon (in 12 counties), and Wisconsin. These states believe such an approach:
    - better integrates physical and mental health care;
    - prevents consumers needing mental health services from "falling through the cracks;"
    - improves medical care, especially for people with severe and prolonged mental illness;
    - is more likely to reduce or eliminate cost shifting and confusion;
    - avoids the possibility that clients are stigmatized;
    - provides greater access in rural areas, where specialty providers may not be available; and
    - could produce savings. (For example, a National Institutes of Mental Health study found that 80% of those who do not consult mental health specialists for mental health problems will seek care from primary care practitioners for physical ailments related to their emotional problems.)[3]
- *Full carve-out model:* Six of these states operate full carve-out mental health programs: Colorado, Iowa, Massachusetts (PCCM program), Oregon, Tennessee, Wisconsin (pilot programs). These states believe a

---

[2] Definitions from The Lewin Group, Inc. for the Substance Abuse and Mental Health Services Administration Managed Care Tracking System. (Phase 1 Draft, 1996).

[3] "Carve-Out Arrangements in Managed Care: Experience Suggests Value Despite Questions About Long-term Viability", *State Initiatives In Health Care Reform* no. 22 (April 1997): 11.

carve-out approach:
- improves the capacity to meet the mental health needs of severe and persistently mentally ill adults and children;
- is an important first step in developing expertise in managed mental health care;
- compensates for mainstream plans' lack of experience, capacity or willingness to provide mental health services;
- improves access by assuring that mental health needs do not "fall through the cracks;"
- alleviates the bias of the traditional medically-oriented managed care system against mental health;
- may operate more effectively and efficiently (professionals who perform large numbers of specialized procedures for certain conditions should enjoy economies of scale[4]);
- may reduce or prevent risk selection;
- allows for reinvestment of savings gained from inpatient and other 24-hour care into other mental health services; and
- clarifies administrative tasks (for example, prior to carving out managed mental health programs, several states noted that many HMOs sub-contracted behavioral health to other organizations, making these services difficult for the state to monitor).

- *Partial carve-out model:* Delaware and Washington both have partial carve-out models, but their models have little in common.
  - Delaware, only allows managed care organizations to provide less acute mental health services. State agencies continue to provide many services (such as psychiatric hospitalization and residential treatment) for adults and children with severe and prolonged mental illness. This system arose from the concern that the managed care organizations did not have the capacity to provide deep-end services.
  - Washington carves-out nearly all mental health services, except those provided in primary care settings, limited psychological testing and one hour per month with a psychiatrist. Washington's community mental health program operates under legislatively mandated regional (county-based) authorities. Supporting the established, if ever-changing, system of care for people with mental illness is the chosen course.

States using partial carve outs seek to tailor their programs to get the best of both strategies.

---

[4] Ibid, p. 8.

Goals of Managed Mental Health Care

States asserted that the issue is not whether to carve out mental health managed care, but how care can best be managed for persons with mental health needs. These states believed that managed care can move the current medically-based system to a system promoting prevention, rehabilitation, and recovery, but emphasized that the goals in moving mental health services or populations into managed care must be clear. They agreed that the goals of mental health managed care are to:

- integrate physical and mental health care to provide a seamless system of care that treats the whole person;[5]
- help individuals with mental illness toward recovery and toward maximizing their choices and independence;
- promote community-based, highly individualized services; and
- use dollars more efficiently.

While there has been considerable criticism about the cost-saving goals of managed care, these states stressed that the current payment system of care for persons with mental illness is not efficient for the consumers nor for the payers. Fee-for-service Medicaid limits the types of services provided and has a strong institutional bias, while managed care has the potential to provide more flexible, consumer-oriented benefits. Most of the 35 states (plus the District of Columbia) offering mental health services through managed care have used the savings from managed care to broaden their service coverage for mental health.[6]

States cautioned that the growing popularity of disease management within managed care is generally inconsistent with the goals of maximizing choice for consumers and providing care that best addresses the needs of the whole person. They cautioned that disease management can be medically-oriented and diagnosis-based while the goals of the managed mental health care system are to further functional capacity and recovery.

---

[5] A study completed by Indiana's Medicaid agency of its non-institutionalized Medicaid disabled population found that nearly 30% of the beneficiaries with a psychiatric diagnosis also had serious physical health problems. Source: Collette Croze, *Medicaid Managed Mental Healthcare.* (Portland, ME: National Academy for State Health Policy, 1995).

[6] From the forthcoming publication by The Lewin Group: *SAMHSA Managed Care Tracking System: Phase I, Executive Summary to Final Report.*

Coordinating Medical and Non-Medical Care

Integrating medical, mental health, and supportive services is complex regardless of whether programs are "carve-out" or "carve-in" designs. Given the complex needs of persons with mental illness, state policymakers are considering new approaches to managed care. For example, Wisconsin established a commitment from managed care organizations to manage all services for specific populations, including people with mental illness. The MCOs involved must show expertise in handling different primary presenting conditions.

State Medicaid programs also need to coordinate with other government funders. Moreover, state programs are challenged to coordinate care among other service networks, such as substance abuse, criminal justice, foster care, housing, vocational, educational, special needs children, child welfare, and others.

For example, in two of its counties Wisconsin carves out behavioral health care for a small group of children with severe emotional disturbances. In the Children Come First program, primary care is provided fee-for-service, while comprehensive behavioral health and support services are provided through a managed care contractor. The Medicaid capitation rate is paid to the counties, which combine it with their own capitation. The state capitation payment covers only Medicaid-covered services, including mental health and substance abuse services. The county's capitation pays for non-Medicaid-covered services, such as respite, mentoring or education aides.

The contractor assigns a lead agency (e.g., a juvenile justice or mental health center) to provide case management based on a child's presenting problems. The case manager is responsible for coordinating one plan—including all physical health, mental health, and ancillary services—developed by the treatment team for each of one to eight families in his/her caseload. The treatment team includes the child and family, as well as professionals (formal supports) and non-professionals (informal supports—people important to the family such as neighbors, clergy or other extended family members). The case manager has full responsibility and authority to obtain mental health and support services and is responsible for coordinating with the primary care provider.

Iowa specifically allows funding for the mental health carve-out program to be used for any services believed to help the client. Program policies require joint treatment planning with other funders as part of authorizing flexible Medicaid funding for these clients. In Delaware, the Medicaid agency pays the Department of Services for Children, Youth and their Families a bundled rate for each child served in the previous month. If the Medicaid agency develops a question regarding the service provided, it retains the reimbursement until the issue is resolved.

Coordinating services remains a challenge for even the most experienced state mental health managed care programs. Integration is often multi-dimensional —benefit packages, payment system, administration, etc. Integrating one area can create fragmentation in another.

Prescription drug policy is an example of this complexity. Drugs are often prescribed by both primary and mental health providers. States struggle with rate-setting and the need to decide whether the primary care or behavioral health plan includes prescription drugs in the capitation rate. No state has resolved the issues around pharmaceutical policy to their satisfaction.

Massachusetts and Delaware exclude pharmacy from the capitation rate and pay for this service on fee-for-service. These states took this approach because they were concerned that good data on pharmacy costs are not available. Massachusetts conducts monthly peer utilization reviews to provide an incentive for doctors to be cost-effective.

While, in Colorado, prescription drugs are included in the HMO rate and not in the BHO's rate, even if prescribed by its providers. Colorado has convened a joint HMO-BHO Pharmacy Committee, facilitated by the state's Medicaid and mental health agencies, to address these issues. Thus far, the Committee has developed a model memorandum of understanding regarding dispute resolution, information sharing, formularies, etc. Most managed care organizations have decided to follow its suggestions.

Also, Tennessee includes prescription drugs in both the HMO and BHO rates. But, has determined specific drugs for which the BHO will always pay (regardless of where the prescription originates).

Finally, an example of the complexity particular to carve-outs is in determining which provider is responsible for services (pharmacy and other) overlapping between mental and physical health. Oregon has identified a list of such services to be covered by the capitation to HMOs, including medication, medication management, and laboratory services.[7]

Engaging Stakeholders

Managing mental health care requires coordination among multiple stakeholders. Stakeholders can have a large influence on decision-making. For example, in

---

[7] Sally Bachman, Ph.D. et al., *Medicaid Carve-Outs: Policy and Programmatic Considerations*, (Princeton, NJ: Center for Health Care Strategies, 1997), Tab H, p. 9.

Oregon,[8] program planners originally envisioned mental health services integrated into the general managed care benefit package. However, county mental health authorities and community mental health centers (which historically provided mental health services) believed their continued viability to be threatened by such an arrangement. Their successful lobbying of the legislature resulted in the program to provide expanded managed mental health services being scaled back from 100% to 25% of the Medicaid population, modified the RFP to allow community mental health centers (as well as fully capitated health plans) to respond, and maintained state-only mental health funding for the counties.

Lessons

- Be clear about the goals for moving mental health services or populations into managed care. Use these goals to determine whether or not to carve out managed mental health care services.
- Realize that regardless of "carving in" or "carving out" managed mental health care, integrating physical and mental health services is a very complex challenge. Integrating one area of care may fragment another in unforeseeable ways.
- Know the managed care community's abilities and willingness to provide mental health services before making the decision to carve in or out.
- Be aware of stakeholder concerns. Work with key stakeholders throughout the process to minimize resistance. Collaboration between Medicaid and mental health agencies is especially important.
- Consider all the services that could be wrapped around consumers. The more system boundaries are removed, the more seamless the system will be to the consumer, and the less likely cost will be shifted or services duplicated. Determine how best to work with other state agencies serving these clients.
- Be cautious about disease management models, which may run counter to the goals of managed mental health care.

---

[8] Ibid, Tab H, p. 4.

Plan and Provider Issues

The capacity to provide effective managed mental health care relies upon a competent and available network of plans and providers. States need to evaluate the capacity of plans and providers and set clear goals for them prior to launching managed mental health care.

Plan and Provider Coordination and Training

States use a variety of approaches in bringing plans and providers together to address the special needs of Medicaid beneficiaries. Realizing the Medicaid program is a public one, some plans recognize if they do not voluntarily share information regarding best practices, the state can identify and share this information independently.

For example, New York plans to contract with consumer groups to provide technical assistance in helping build the capacity of plans and providers and to encourage them to do business differently. Consumer organizations will also be contracted to teach plans and providers some creative ways to provide services.

Similarly, Wisconsin's AFDC HMO initiative convenes regional mental health/substance abuse work groups that include members from their HMOs, BHOs, substance abuse providers, subcontractors, consumers, counties, and advocates to discuss the effectiveness of treatments and brainstorm ways to improve. This information sharing helps assure that the system is continuously improving. It also gives technical assistance to all plans and providers, in both mental health and primary care.

Massachusetts requires consumer input at the plan level by requiring each MCO to have an advisory group made up of consumers and providers. The Medicaid agency also convenes ongoing meetings with the Department of Mental Health, Department of Medical Assistance, and managed care organizations to discuss specific indicators such as access, quality, system development, and financing.

Finally, Iowa is developing the capacity to profile providers. These profiles are shared among providers at monthly provider roundtables and summary information is made available to the public. The roundtables allow discussions of provider profiling, consumer and provider satisfaction results, quality assurance and other current issues, and provide a forum for providers to train other providers on what does and doesn't work.

States warned that providers working in BHOs need to learn new behaviors. Some providers are very happy in the new environment; they feel there is an opportunity to be creative in the delivery of services they did not have in the fee-for-service

Medicaid system. Other providers view managed care as being too regulatory and requiring too much data.

States need the capacity to continuously monitor providers and their networks. States can require contractors to periodically review their subcontractors and report the results back, or can contract directly with providers.

Community-Based Providers and Financing Issues

In the transition to managed mental health care, many changes occur in the service delivery system, resulting in winners and losers. States agreed the argument is not which essential community providers should be supported, but rather what essential community services must be retained to provide the best care for beneficiaries. Community Mental Health Centers (CMHCs) and public mental health programs are often challenged by state Medicaid initiatives in mental health managed care. These traditional, essential community providers have had to change and compete—confronted with new expectations for management, accounting, quality assurance, and other requirements of managed care.

Massachusetts, for example, held CMHCs harmless during the first year of mental health managed care. The state felt this gave CMHCs a chance to learn how to function in the managed care environment. In Wisconsin, smaller providers feared they would be forced out of business, because they were not offered a subcontract from a plan or they could not compete with larger providers. To counter this problem, a memorandum of understanding (MOU) was established between county mental health boards and HMOs. The HMOs are required to sign a memorandum with all qualified mental health providers. Oregon takes the more direct approach of giving their county mental health system first right to refuse the BHO contract. Finally, in Delaware, the Medicaid agency encouraged MCOs to contract with community child mental health providers. As a result, nearly all have become MCO providers.

Reimbursement influences plan and provider behavior. Historically, Medicaid has been viewed as a provider entitlement in which discrete services were reimbursed to certain predetermined providers. Managed care allows considerable flexibility and consumer direction in developing plan and provider networks and benefit packages.

As Medicaid programs capitate mental health benefits, community-based mental health providers may lose some funding because managed care organizations only buy certain services from them. Absent those additional Medicaid dollars, CMHCs will have difficultly sustaining their traditional range of services. Historically, in some states Medicaid dollars supplemented CMHC services and allowed them to serve the uninsured. States reported they have seen less impact on access for the uninsured, but more impact on "soft services" such as counseling and marriage counseling.

If behavioral managed care is successful, deinstitutionalization will increase resulting in empty hospital beds and creating a funding problem for state hospitals and community hospitals that serve as inpatient mental health units. States noted that the speed and size of reductions in inpatient care was astonishing. Such changes should be viewed as a result of managed care, *not* poor care; good managed care will reallocate money to where it is needed most.

The choices states make to select plans and providers will affect consumer satisfaction and the program's success. States stressed that individuals should not be made to choose between their primary care provider or their mental health provider; every effort should be made to coordinate the two. States encouraged program developers to consider a team of providers as the PCP.

Lessons

- States should be specific about what they want to buy in managed care and build strong expectations for consumer involvement and choices.
- Plans and providers need technical assistance and training. Managed mental health care is different from fee-for-service; you cannot expect providers or plans to immediately change their way of doing business overnight. Be realistic with goals.
- Building the capacity of plans and providers should be a team effort on everyone's part—state, consumers, plans, and providers.
- Defining 'success' in mental health managed care should be a public process.
- Large-scale reduction of inpatient care will happen rapidly. Expect and prepare for significant impact on hospitals, especially state-run facilities and prepare for continuous access to outpatient care amidst this downsizing.
- Expect and create constant input. If you think you have talked with everyone, you haven't.

Oversight/Monitoring Quality

Determining Goals

The critical first step to monitoring quality is to be clear about the expected results of services for consumers, plans and the system.

Several states noted the importance of engaging stakeholders early on to determine goals and how they ought to be measured. However, various stakeholders often have conflicting goals and priorities; balancing these views can be challenging. In order to gather public input, New York's Quality Assurance Task Force surveyed approximately 2000 stakeholders regarding desired outcomes. Massachusetts made 'the public' an active participant in the contract development process by convening workgroups of different stakeholders, which created standards included in the purchasing specifications. While, Iowa used a Request for Information process to obtain stakeholder input on performance measures. Sixty indicators developed are now in use.

States stressed that the standards traditionally used by commercial managed care organizations may not work for non-commercial populations. One way to work around this is to create evaluation teams for the creation and review of the requests for proposals including the Medicaid agency, mental health departments, other state agencies, and consumers.

From a consumer's perspective, the goal of managed mental health care is to assist recovery and build functional capacity. This can be measured in "non-medical ways" such as the capacity to hold a job or participate in school. Such quality of life issues can be difficult to define. Wisconsin's Children Come First program's performance measures include the child's success in school, lack of involvement with the juvenile justice system, and expressed family satisfaction.

Measuring Success

Quality assessment calls for observing and collecting information on three aspects of care.

- The "structural" elements, such as accreditation status of a health plan.
- The "processes", or what practitioners do to and for their patients from prevention and screening to diagnosis, treatment, rehabilitation or support services.

- The "outcomes", both short-and long-term.[9]

States are moving toward stressing accountability of outcomes or results, rather than simply accountability of finances. However, the science of outcome measurement has not sufficiently advanced to rely on these measures exclusively. Efforts currently underway to develop such outcomes include:

- The Center for Self-Help Research at the University of California at Berkeley developed an empowerment scale examining the person's ability to make decisions on concrete issues in his/her personal life, meeting basic needs, and participating in organizations.[10]

- The Center for Psychiatric Rehabilitation at Boston University developed an empowerment scale used in consumer-run self-help programs. It examines such issues as control over one's life, achievement of goals, self-esteem and self-efficacy.[11]

- The outcome measurement system developed by the University of Cincinnati's Quality Center is now being used in 12 states. It tracks four measures: mental health symptoms, daily social functioning, perception of physical health and patient satisfaction.[12]

- The Child Welfare League of America's Odyssey Project is examining outcomes for about 2,500 emotionally disturbed children and teens in residential settings. Outcomes to be examined at the end of treatment include: placements into less intensive settings, family reunifications and adoptions, educational achievements, level of life skills, behavioral problems, and social competencies. Outcomes at one- and two-year follow-ups include: employment, educational achievement, personal satisfaction with life, satisfaction with services, connections

---

[9] Avedis Donabedian, "Evaluating the Quality of Medical Care," *Millbank Memorial Fund Quarterly* (July 1966): Part 2.

[10] Steven Segal, Carol Silverman, and Tanya Temkin, *Empowerment Scale*, (Berkeley; CA: Center for Self-Help Research).

[11] Center for Psychiatric Rehabilitation, *Making Decisions: Empowerment Scale*, (Boston University, Sargent College of Allied Health Professionals).

[12] "Outcome Measurement Grows; Defense Ponders National Rollout", *Managed Behavioral Health News* 3, no. 12, March 27, (1997): 1

with family and friends, contacts with juvenile and criminal justice, and alcohol and drug use.[13]

In addition to any available outcome measures, states monitor quality through such process measures as:

- *Access* - maximum distance to a hospital, maximum time for response to a phone call, maximum wait at an emergency room or for a hospital bed, etc.
- *Types of providers* - children's providers, gerontologists, social service providers, etc.
- *Ability to serve special needs populations* - individuals dually diagnosed with mental illness and substance abuse issues, children in foster care, etc.
- *Caseload ratios* especially with regards to special populations
- *Quality indicators* such as those in HEDIS.

In its first bid for mental health managed care, Massachusetts held plans accountable to the measures listed above. Now in its second bidding process, the state has added these criteria:

- Length of time the consumer is in the community
- Length of time the consumer is in a single living situation which he/she likes
- Ability of the consumer to participate in school or work (including supported work).

Delaware's performance indicators for the Child Mental Health Public/Private Partnership[14] include:

- Effectiveness

---

[13] Robert Cunningham, "Outcomes Hard to Track in Kids' Behavioral Care," *Medicine and Health Perspectives* (January 20, 1997).

[14] Diamond State Health Plan, *A Public MCO Innovation: The Role of the Division of Child Mental Health Services in Medicaid Managed Care's Child Mental Health Public/Private Partnership,* (Delaware Department of Services for Children, Youth and Their Families, February 1996).

  - Client improvements on pre/post symptoms and community functioning
  - Consumer satisfaction
  - Low rates of unplanned readmissions, premature discharges, failed transitions

- Efficiency
  - Average cost per quintile of population served
  - Controlled lengths of bed stays, hospital and residential treatment
  - Cost per admission to deep end services

- Appropriateness
  - Levels of intervention based on levels of severity; judicious use of bed resources
  - Clients move toward less restrictive levels of care
  - Parents participate in treatment planning
  - Treatment team leaders validate selection of level

- Accessibility
  - Services are geographically accessible
  - Services are equally available across age range
  - Minority groups are appropriately represented across levels
  - Service populations represent various disability groups
  - Follow-on services, e.g., for 17 year olds, are accessible

- Provider Capacity
  - Adequate service capacity in various levels to accommodate inflows
  - Adequate support for intake/assessment, clinical services management, provider administration
  - Clients move appropriately between commercial MCOs and public MCO (managed by the Division of Child Mental Health)

Using the Data

Once goals are in place, specificity of desired results in the procurement and contracting process can keep states in control of the process. However, while an outcome can be specific, the state may not want to spell out the means to that outcome. For example, if reimbursement is limited to only the covered services enumerated, new service development can be slowed or prohibited. States suggested the following contract provisions.

- The performance standard expected; (if available) the outcome desired

- The type(s) of data necessary to show that this standard/outcome has been met
- The method for gaining this data
- The definition of non-compliance to the standard/outcome and the sanction(s) for that non-compliance.

Determining performance standards and targets is difficult without having prior data to show what is reasonable. Trying to compare services delivered through risk-based managed care and fee-for-service systems does not work well, for several reasons. Different organizational structures make comparison difficult. Managed care may provide more flexible benefits than fee-for-service. Fee-for-service beneficiaries may experience access barriers which would affect their use of services. Managed care is often provided in more urban areas, complicating comparisons with fee-for-service, which may have a more rural focus. In many areas, data is incomplete or not comparable between fee-for-service and managed care.

Focusing on what is realistic—as opposed to what is merely possible—makes for a stronger contracting and monitoring process. The staff time needed to monitor quality —in most cases already more complicated and time-consuming than overseeing the fee-for-service system—increases with every additional measure to be evaluated. (Tennessee noted that the 110 performance measures in its initial contract were too many for appropriate measurement and reporting. Those measures have been reduced to 33.) Also, there may not be enough people receiving a certain type of care for its meaningful evaluation. Finally, the contractor being evaluated must be able to affect the issue being measured.

Monitoring takes place at multiple levels—the managed care organizations, the behavioral health organizations, providers, etc. States must also monitor the system as a whole, as changes made in one area may affect other areas in unforseen ways.

Monitoring also involves other state agencies. In its children's program, Delaware's Medicaid agency holds the Division of Child Mental Health Services accountable by withholding the reimbursement if problems with services arise. Agencies can also work together to monitor managed care organizations and providers. Data collected by one agency may be valuable as performance measures to another agency's monitoring efforts. For example, in Washington, payroll data submitted to the Department of Employment Security is being used to measure employment outcomes for people served in the mental health, developmental disability, substance abuse and vocational rehabilitation systems. While for Wisconsin's Children Come First program, the Medicaid and mental health agencies share data collected by the mental health agency. Both agencies negotiate contracts together and share staff for monitoring.

Monitoring must provide immediate results as well as long-term results. Tennessee implemented consumer cohort studies to gain immediate feedback on the system. When starting the program, Iowa kept daily track of treatment authorizations and inpatient utilization in order to combat public fears that enrollees would not be able to obtain services.

Quality monitoring needs to take a multi-pronged approach. Monitoring mechanisms used by states include:

- advisory committees, including members of different stakeholder groups;
- spot inspections; and
- consumer input (see Consumer Involvement section).

Lessons

- Involve stakeholders in developing goals and performance standards. National standards may be less important than standards desired by stakeholder groups. In Iowa, stakeholders consisted of anyone who chose to respond to the Request for Information. Wisconsin's Children Come First program worked with a family advocacy group, Wisconsin Family Ties, to design a family satisfaction tool.
- Create evaluation teams for the creation and review of the RFPs including the Medicaid agency, mental health departments, other state agencies, and consumers.
- Staff time needed to conduct oversight and monitor quality is significant.
- State agencies working together can improve the effectiveness of oversight. Data collected by one agency may be valuable as performance measures to another agency's monitoring efforts. Agencies may have to work out agreements regarding how to share data.
- Focus on performance standards that are realistic for plans to gather meaningful data and for state staff to manage and evaluate.

- Specificity of desired results in the procurement and contracting process can allow states to remain in control of the process. Contract provisions should include:
  - The performance standard expected; (if available) the outcome desired
  - The type(s) of data necessary to show that this standard/outcome has been met
  - The method for gaining this data
  - The definition of non-compliance to the standard/outcome and the sanction(s) for that non-compliance.

- Monitoring must provide immediate results as well as long-term results. In the early days of its program, Iowa used authorization data to build public confidence that the door to mental health care remained open and that services were being provided. Colorado conducted extensive evaluations of pilot projects prior to expanding them.

- Monitoring takes place at multiple levels—the managed care organizations, the behavioral health organizations, providers, etc. States must also monitor the system as a whole.

Consumer Involvement

States agreed on the importance of including consumer and family member involvement in all aspects of managed care, including benefit design, rate setting, contracting, governance, monitoring and oversight. Outcome measures, in particular, must incorporate consumer input to accurately evaluate effectiveness. States stressed the importance of the commitment to both seeking out consumer input, and to using this input in crafting and fine-tuning programs.

It was noted that adults with mental illness generally wish to represent themselves and not be represented by family members who may have different goals. On the other hand, families are important stakeholders in children's mental health programs.

States use a variety of approaches to assure consumer involvement. A multi-pronged approach increases the chances that the information gathered represents the views of a wide variety of consumers. For example, Massachusetts and Colorado require managed care organizations to have consumers and family members on advisory groups. Colorado also held approximately 20 focus groups with adult consumers, family members of adult consumers, and parents of child consumers. They increased participation by offering child care and refreshments, and by having Community Mental Health Centers (CMHCs) mention upcoming groups to clients. MCOs, not allowed to be present, are provided post-focus group feedback.

Washington conducts 20-minute interviews with consumers on such issues as access, voice and ownership of the treatment process. Finally, New York is developing a peer education program in their Prepaid Mental Health Program. Beneficiary-run organizations will receive funding to assist beneficiaries learn about the program and to monitor enrollment practices.

Some states have found it especially difficult to get children and adolescents as well as their families to the planning table. States have used strategies such as paying for gas and child care, but noted it was also important to have staff support for the consumers and family members to educate and support them in understanding the issues.

Many states use consumer and/or family member satisfaction surveys, but stressed that by themselves they may be of limited use. More useful information may be obtained by asking consumers about improvements in their quality of life or ability to live independently.

Consumer input can also be gained through grievances and complaints. States gain this type of input through:

- offering consumer hotlines and 800 phone numbers;
- employing consumer advocates;
- studying plan disenrollment and switching;
- aggressively reviewing informal complaints; and
- establishing ombudsman programs outside the system

Delaware found that many Medicaid beneficiaries speak freely with enrollment brokers. The beneficiaries recognize these brokers as independent of either the plans or the state. The brokers are often available at community areas, and considered responsive by Medicaid beneficiaries. To take advantage of this, the state combined ombudsman and enrollment functions. However, others worry that the independence of the enrollment brokers will be compromised if they take on responsibilities for complaints and grievances.

Using peer leaders to educate consumers on their rights and responsibilities as managed care enrollees was stressed. Some states also use special care coordinators who teach persons with mental illness how to enroll and use the system with no disruption of care.

Initiatives under way may prove effective in facilitating consumer involvement. For example, the Foundation for Accountability (FACCT), an organization primarily of consumer and purchaser representatives, is seeking to develop new performance measures for managed care that are patient centered.[15] Brandeis University has developed a Consumer Access, Voice and Ownership (CAVO) survey.

Finally, mechanisms must be in place to assure that consumer input is used in planning or modifying the program. Feedback loops create ways to make sure such input is used.

Lessons

- Consumer involvement must be early and regular throughout program development, operation and monitoring. Resources must be invested to successfully obtain and use consumer input.
- Use multiple strategies to obtain consumer input. One mechanism (such as a consumer satisfaction survey) may be of limited usefulness.
- Consumers do not speak with one voice. Issues are different for different populations of consumers, family members, etc. Be sure consumer engagement is culturally sensitive and that samples are stratified.
- Medicaid programs should reach out to mental health programs for input from consumers and nomination of consumers to participate on advisory councils, etc.
- Complaints and grievances can not be overlooked as a source of consumer input.
- Build in feedback routes to assure that consumer input is used in planning or modifying the program.

Administrative Issues

States need significant time and resources to successfully implement managed mental health care and to develop new relationships among state agencies, with consumer groups, and with other stakeholders. Issues to be worked out include claims processing, data and payment systems. Colorado spent three years in the

---

[15] Alice G. Gosfield, "Who Is Holding Whom Accountable for Quality?," *Health Affairs* 16, no. 3 (May/June 1997): 35.

planning process and had a relatively smooth implementation process and consumer transition, but even then, unexpected administrative issues arose.

New partnerships need to be formed at the state level as well as the county, regional, and local levels, depending on how providers are organized. Needed training should be coordinated among states' mental health and Medicaid programs, MCOs and local providers.

States warned that cost-shifting is real during periods of transition, particularly between institution- to home-treatment. It was suggested that contractors pay transition costs to minimize cost-shifting.

Rate-Setting and Risk Sharing

There does not seem to be one best way to set rates that guarantees states are paying properly for services. Many states agreed that it is difficult to acquire and synthesize all the data needed to set rates and determine risk sharing arrangements.

Colorado uses historical fee-for-service claims data, geography, age, eligibility category, and health status to set rates. The State planned to establish a stop-loss pool, which would withhold part of the BHOs' capitation rate to offset high cost consumers, but the BHOs felt confident they could take on the risk themselves. Oregon uses an actuary firm to set rates. However, the actuary firm must make many assumptions in determining rates, so the State does not know whether they are paying too much or not enough. BHOs in Oregon must participate in the State's stop-loss insurance or to self-insure. Finally, Massachusetts has established risk corridors and is considering adopting a case-mix payment approach.

Soon after converting medical and mental health systems to managed care, Massachusetts' Medicaid agency realized many beneficiaries were also receiving services through the Department of Mental Health. The two agencies have developed a relationship in which the Department of Mental Health transfers money to the Medicaid agency to cover mental health services supplied by MCOs. Medicaid covers acute services; the Department of Mental Health covers continuing care, quality, clinical oversight and policy.

States expressed interest in limiting MCO profits, but noted that such initiatives were very easy to "game", and that plans may need higher administrative payments to meet quality standards.

Data Systems

Information needed for quality assurance, program planning, and setting future capitation rates is obtained in part by tracking high-cost consumers, identifying areas of underservice, and identifying gaps in continuity of care and preventative care. States also stressed the importance of tracking the authorization of services and ensuring the services authorized were actually delivered. In managed care, Medicaid agencies do not receive claims information directly from providers, but instead from the plans, making this information more difficult to come by. Problems arise even when data is available since plans', providers', and states' different systems are difficult to coordinate, and definitions and outcome measures are not standardized. Many states reported difficulties setting up data systems, but agreed that it is worth the effort.

In Connecticut, lack of time and support were barriers to setting up a data system. They also encountered problems such as the claim system not being linked to the eligibility system, creating problems determining the number of clients to pay capitation to the BHO on a monthly basis. Other states expressed concern about eligibility management issues and how to handle retroactive eligibility in paying plans.

Delaware's Division of Child Mental Health Services has established a data system that provides immediate and accurate information on every child in the system. It allows the Division to track: service demand, rates of referral, unduplicated number of clients served in the month, service loads at the various levels of care, and psychiatric hospital days. However, the state is having trouble tracking clients across systems.

Contracting

States were not in agreement on what format the contract should take. Some felt it should be very specific with services listed, with the desired outcomes and stipulations if the outcomes are not met. Those in disagreement felt that stringent contracting confined MCOs, not allowing them to be creative in developing cost-effective approaches to care.

Colorado establishes a minimum package of benefits MCOs must provide, but provides no ceiling or limits. Washington is reluctant to have all measures and outcomes specified in their contracts for fear BHOs will only perform to those standards. They believe the contract needs to be flexible depending on the organization and population, since many outcomes vary by population. Finally, Massachusetts requires aggressive purchasing specifications to assure services provided are designed for the population being served and not carried over from a general MCO's contract. All MCOs are granted financial incentives if quality standards are met in their 6-month reviews. The state often increases standards, striving for continuous quality improvement.

States can require plans to include specific services appropriate to a consumer's diagnosis in the benefit package. In Wisconsin, if the state finds that it is an unrealistic expectation for the network to provide a service, the state allows beneficiaries to disenroll and the state pays fee-for-service. If the service should be available in the network and isn't, the plan must pick up the cost. The reimbursement arrangement is developed so MCOs are not penalized if their network cannot provide all services.

Lessons

- It is important for states to evaluate the capacity of plans and providers and set clear goals prior to launching managed mental health care.
- Be careful about how managed mental health care is promoted. Some states increased expectations, promising to manage outcomes, but insufficient outcome measures exist to prove this promise.
- Clear standards and monitoring strategies, with data systems which can collect needed information, must be in place. Before transitioning to managed care, all participating state agencies, plans, and providers should convene to discuss data needs and collection strategies.
- Rate-setting strategies need to be developed carefully in consideration of the diverse needs of the population being served.
- Work towards eliminating system boundaries to increase flexibility and decrease duplication of services.

Conclusion

No single model has yet emerged on how to best meet the needs of the person with mental illness in a managed care environment. Some states carve out mental health services, others integrate those services within traditional HMOs, while still others include some services within HMOs while offering other services through specialty providers. States participating in the symposium concluded that each state, working with consumers and key stakeholders, would need to identify its own approach to meeting these four goals:

- Integrate physical and mental health care to provide a seamless system of care that treats the whole person
- Help individuals with mental illness toward recovery and toward maximizing their choices and independence
- Promote community-based, highly individualized services
- Use dollars more efficiently.

Development of appropriate plans and providers requires a focus on the special needs of persons with mental illness. Plans need the capacity to develop and obtain the wide range of services needed by persons with mental illness. Benefits need to be designed to provide sufficient accountability but still allow enough flexibility to encourage plans to develop individualized, consumer-sensitive care approaches and to overcome the institutional bias of fee-for-service Medicaid. Because persons with mental illness need a range of services and supports, managed care programs should maximize coordination with other services (educational, juvenile justice, vocational, supportive, etc.) assisting the beneficiary.

Clear expectations, reflecting consumer input, must be monitored carefully. These expectations must recognize that managed mental health care is a work in progress, particularly regarding the appropriateness of rates and risk-sharing adjustments. States will be challenged to develop effective systems of managed mental health care. They need sufficient resources (staff, data capacity, quality oversight, consumer and stakeholder involvement) to meet the task.

Department of Health and Human Services

OFFICE OF INSPECTOR GENERAL

Retooling State Medicaid Agencies For Managed Care

JUNE GIBBS BROWN
Inspector General

August 1997
OEI-01-95-00260

OFFICE OF INSPECTOR GENERAL

The mission of the Office of Inspector General (OIG), as mandated by Public Law 95-452, is to protect the integrity of the Department of Health and Human Services programs as well as the health and welfare of beneficiaries served by them. This statutory mission is carried out through a nationwide program of audits, investigations, evaluations, sanctions, and fraud alerts. The Inspector General informs the Secretary of program and management problems and recommends legislative, regulatory, and operational approaches to correct them.

OFFICE OF EVALUATION AND INSPECTIONS

The OIG's Office of Evaluation and Inspections (OEI) conducts short-term management and program evaluations (called inspections) that focus on issues of concern to the Department, the Congress, and the public. The inspection reports provide findings and recommendations on the efficiency, vulnerability, and effectiveness of departmental programs.

OEI's Boston Regional Office prepared this report under the direction of Mark R. Yessian, Ph.D., Regional Inspector General. Principal staff contributing to the report included:

Boston Region	Headquarters
Joyce M. Greenleaf	Jennifer Antico
Dana L. Miller	
Russell W. Hereford	
Lynne Hostetter	

To obtain a copy of this report, please contact the Boston Regional Office by telephone at (617) 565-1050 or by fax at (617) 565-3751.

EXECUTIVE SUMMARY

PURPOSE

To identify the major organizational challenges State Medicaid agencies face as they shift their focus to managed care and to offer preliminary assessments of how the agencies are responding to these challenges.

BACKGROUND

At a rapid pace, most State Medicaid programs are shifting their enrollees from traditional fee-for-service health care to managed care arrangements. These still evolving arrangements include primary care case management (PCCM), comprehensive, full-risk managed care, and capitated carve-outs of particular services, such as mental health.

For the Medicaid agencies, this transition is fundamental. They are faced with retooling themselves, much like private corporations do when entering new markets or introducing new product lines. This inquiry defines the key challenges these agencies face in making this adaptation and offers feedback on how they are meeting them. It is based on a review of the experiences of 10 State Medicaid agencies strongly committed to managed care.

MANAGED CARE PENETRATION

The degree and type of Medicaid managed care penetration in the State has a major bearing on the organizational challenges facing a Medicaid agency. The more that Medicaid beneficiaries are enrolled in managed care of any kind and in full-risk managed care in particular, the more that agency management finds itself compelled to uproot its fee-for-service infrastructure and develop new organizational tasks, roles, and structures.

We have identified three stages of penetration. Stage III represents what we call the breakthrough point. At that point, nearly all Medicaid enrollees are in full-risk managed care. Staff redeployment is extensive. The fee-for-service sector no longer dominates. Only 1 of the 10 agencies has reached this stage. Among the others, five are in Stage I, four in Stage II.

CHALLENGES AND RESPONSES

We have identified five major organizational challenges. They are by and large sequential. Most States have considerable experience in addressing the first two, but have barely begun to address the last three challenges. Below we present the challenges and characterize the agencies' responses to them.

Establishing core developmental teams.

The agencies have experienced much success in establishing teams drawn almost entirely from staffs of Medicaid and other State agencies. A downside is that they tend to be isolated from the fee-for-service operations, making it more difficult at times to carry out budgeting and other agencywide functions.

Acquiring necessary knowledge and skills.

The agencies have made extensive use of consultants for ratesetting, computer modifications, and other functions. Few agency staff have experience in the managed care industry. With outmoded State personnel systems and minimal investments in staff training, the agencies face significant constraints developing sufficient staff expertise.

Instilling a new mission and culture.

In most cases, this challenge has barely been addressed, with staff concerns mounting. Some promising strategies, however, are apparent. One is to foster value-purchasing as a goal pertinent to both fee-for-service and managed care sectors. Another is to organize work units in ways that integrate roles across the two sectors.

Redeploying fee-for-service staff.

Once again, this challenge has barely been addressed. In nearly all States, the heaviest users of health care services remain concentrated in fee-for-service sector, thereby minimizing opportunities for staff redeployment. But pressures to move in this direction are building as managed care enrollment accelerates.

Avoiding a fee-for-service meltdown.

Some danger signs are apparent. Less innovation, lower morale, and slower responses in Medicaid fee-for-service sector jeopardize Medicaid service and oversight roles. These danger signs are especially apparent with respect to the following traditional fee-for-service functions: third-party-liability, surveillance and utilization review systems, and drug utilization review.

RECOMMENDATIONS

In State Medicaid agencies, State legislatures, and the Health Care Financing Administration, retooling has been a low-priority issue. In each sector, the focus has been on the substance of managed care efforts and on their effects on providers, beneficiaries, and taxpayers.

As Medicaid agencies approach and enter Stage III, they will be compelled to devote more attention to the retooling issue. The HCFA, as the Federal partner in the Medicaid program, can encourage and help them to address this issue constructively. Our recommendations are made in that context.

The HCFA should provide forums to help State Medicaid agency managers take advantage of the opportunities managed care presents for retooling their agencies and to minimize the associated dangers.

These forums could be at the national level, through the establishment of a work group or technical advisory group, as well as at regional levels, through the efforts of regional offices.

The HCFA should revise its review and monitoring protocols so that they devote greater attention to how State Medicaid agencies are handling the organizational challenges associated with expanded managed care.

Particularly as agencies approach and enter Stage III, it is vital that the retooling issue be taken off the backburner, where it typically resides, and be given major attention. The HCFA can encourage such change by giving greater attention to the organizational challenges when it reviews State agency plans and activities.

The HCFA, in its ongoing reviews of State Medicaid agencies, should scrutinize possible adverse effects of managed care expansion on the performance of established fee-for-service functions.

This matter, we are suggesting, warrants special attention, especially as it relates to the third-party-liability, surveillance and utilization review subsystems, and drug utilization review functions.

COMMENTS ON THE DRAFT REPORT

We solicited and received comments on the draft report from HCFA, the Acting Assistant Secretary for Health (ASH), and the Assistant Secretary for Planning and Evaluation. The latter concurred with our recommendations without further comment. The complete text of the HCFA and ASH comments appear in appendix B. Below we summarize their comments and, in italics, offer our response.

The HCFA concurred with the first two recommendations and partially concurred with the third. It noted that ongoing activities and action taken in response to the first two recommendations would lessen the need for scrutinizing possible adverse effects of managed care expansion on fee-for-service functions. In addition, HCFA suggested that the States discussed in the report be given opportunity to comment on the report and that our reference to "danger signs" in the fee-for-service sector be changed to "concerns." *We decided to retain the former term because it more accurately reflects what we heard and found in the study States. At the same time, as we note in the report, we refer to danger signs in the context of early alerts that could emerge as significant problems if not adequately addressed. As for obtaining reactions from the States, we have received and* *taken into account considerable comment from the States in the course of framing our findings and recommendations.*

The Acting Assistant Secretary of Health did not comment on the specific findings or recommendations in the report, but did offer four suggestions that could enhance the transition process to Medicaid managed care. They are helpful suggestions that warrant consideration by the States and HCFA. They concern the involvement of the State health departments in the managed care process, the need for broad stakeholder involvement in the process, the need to strengthen the integration of public health concerns into the change process, and the importance of strengthening compliance, monitoring, and evaluation at the State level.

TABLE OF CONTENTS

INTRODUCTION

PURPOSE

Our purpose in this inspection is twofold: (1) to identify the major organizational challenges State Medicaid agencies face as they retool their agencies to support the growth of Medicaid managed care and (2) to offer preliminary assessments of how the agencies are responding to these challenges.

TRANSFORMATION OF STATE MEDICAID AGENCIES

Most State Medicaid agencies are undergoing rapid transformation. They are shifting from a traditional focus on fee-for-service health care to one increasingly defined by managed care. The managed care arrangements will involve any one or mix of the following: (1) primary care case management (PCCM), (2) comprehensive, full-risk managed care, and (3) capitated carve-outs of particular services, such as mental health, substance abuse, or dental services (see appendix A).

In this environment, the managers of State Medicaid agencies face an imposing new set of responsibilities that call for them to apply sound business practices and remain closely attuned to the health care marketplace. In both these respects, they find little guidance in the past policies and practices of their agencies.

In recent years, articles, books, and reports have been produced that explain these new responsibilities and that indicate how the States have been responding to them.[1] There has been much less attention to the organizational challenges the Medicaid agencies confront as they carry out their new managed care responsibilities.[2] Yet, the challenges are fundamental.[3] They call for the agencies to reengineer themselves, much like private corporations would when entering a new market or developing a new product line. How well the agencies make this adaptation could well have a major bearing on the long-term success of their managed care efforts. It is a matter warranting further inquiry.

State Medicaid Agency
Managed Care Responsibilities

- *Defining types of managed care.*
- *Developing health plan contracts.*
- *Negotiating rates.*
- *Educating beneficiaries.*
- *Educating providers.*
- *Ensuring patient access to providers.*
- *Coordinating with other agencies.*
- *Meeting with stakeholders.*
- *Developing new data systems.*
- *Overseeing health plans.*

THIS INQUIRY

This inspection focuses on the internal adjustments facing State Medicaid agencies as they move toward managed care. It starts out by addressing how these adjustments are influenced by the extent of Medicaid managed care in a State. It then identifies the major organizational challenges faced by the Medicaid agencies as they increase their commitment to managed care and addresses how they have been responding to those challenges.

In tackling this topic, we recognize that any generalizations about the Medicaid program that cross State boundaries can be hazardous. An often expressed adage among Medicaid directors is: "If you have seen one Medicaid program, you have seen one Medicaid program."[4] Yet in a broad sense, currents of change are apparent among the States and are helpful to highlight, even if they do not adequately reflect what is happening in any individual State. In our synthesis observations, we focus on those currents. To reflect some of the diversity that exists and to minimize the danger of our becoming too abstract, we offer examples of developments occurring in particular States.

Our inquiry is based primarily on a review of the recent experiences of 10 State Medicaid agencies that have made strong commitments to Medicaid managed care. The States are diverse in terms of their location, size, and experience with managed care.[5] They are clearly among the top half of States in terms of the proportion of their Medicaid beneficiaries in managed care. For each of the States, we interviewed agency officials and reviewed pertinent documents. In three, we conducted in-depth visits that also included interviews with representatives of health plans, advocacy groups, State legislatures, other State agencies, and Medicaid enrollees.

Our inquiry does not address the internal adjustments that the move toward managed care presents for other State agencies, such as those focusing on mental health, public health, mental retardation, elder affairs, and social services. These adjustments can be significant since Medicaid often serves as a major source of funding for their service operations and since managed care can lead to major changes in these operations. The organizational effects in these other agencies warrant attention. But with the reverberations of managed care likely to be most immediate and consequential within in the Medicaid agencies, we have decided to concentrate this inquiry on them.

We conducted this inspection in accordance with the Quality Standards for Inspections issued by the President's Council on Integrity and Efficiency.

MANAGED CARE PENETRATION

The degree and type of Medicaid managed care penetration in a State has a major bearing on the extent of the organizational challenges facing the State Medicaid agency.

The challenges we are examining in this report do not occur in a vacuum. Both the extent and nature of the challenges are heavily influenced by numerous factors, many of which are beyond the control of agency management. Among the more important of these shaping influences are: the rapidity of the movement toward Medicaid managed care;[6] the extent of managed care in the private marketplace;[7] the extent of the agency's prior experience with managed care;[8] the size of the State's Medicaid program;[9] the complexity of the managed care program;[10] and the extent and manner in which other State agencies regulate managed care organizations.[11]

As important as these factors are, we learned that another factor is likely to have a more enduring effect on the challenges facing agency management as it seeks to gear up its organization to carry out managed care responsibilities. It involves the degree and type of Medicaid managed care penetration in a State. The more that Medicaid beneficiaries are enrolled in managed care of any kind and in full-risk managed care in particular, the more that agency management will find itself compelled to uproot its well-established fee-for-service infrastructure and develop new organizational tasks, roles, and structures.

Among the 10 States we reviewed, we identified three key stages of Medicaid managed care penetration (see table 1):

TABLE 1 STAGES OF MEDICAID MANAGED CARE PENETRATION				
Stage	Managed Care Enrollment	Full-Risk Managed Care Enrollment	Organizational Implications	States
I	Substantial. Can include majority of caseload.	Negligible to moderate.	Modest. Agency forms core managed care staff. Adjustments in computer systems, provider relations, and beneficiary education.	MA NY FL OH MO
I	Majority of caseload.	Dominant mode.	Substantial. Agency redefining itself as purchaser of health care. Major focus on enrolling beneficiaries and overseeing health plans.	CA RI MN UT
III	Nearly all of caseload.	Dominant mode.	Far-reaching. Agency reaches breakthrough point. Extensive staff redeployment. Fee-for-service sector no longer dominant.	OR

In Stage I, the Medicaid agency has made a substantial commitment to managed care--one that is likely to encompass most or all of the families with dependent children and perhaps even some of the aged, blind and disabled beneficiaries. Some of these individuals may be enrolled in full-risk managed care, but most are likely to be in PCCM and/or carve-out arrangements. This change calls for some adjustments in traditional agency operations. But the reverberations are relatively contained because the fee-for-service system remains essentially intact. Beneficiaries in PCCM and carve-out arrangements continue to receive much care from providers who continue to bill Medicaid for each episode of care.[12]

In Stage II, the critical difference is that full-risk managed care becomes mainstream. The agency begins to reposition itself as a purchaser of services from relatively few health plans rather than as a payer of bills from thousands of providers. In one way or another, more and more agency staff are involved in defining, supporting, and overseeing the work of health plans. The demands on the fee-for-service sector of the agency begin to diminish and staff accustomed to working on functions such as prior authorization or surveillance and utilization review must learn new roles. In this milieu, reorganizations are common.

In Stage III, full-risk managed care becomes even more dominant to the point where it encompasses many or even most of the aged, blind, and disabled beneficiaries. Although a minority of the caseload, they have accounted for a majority of agency expenditures and claims processed. As such, they have been instrumental in sustaining the fee-for-service sector of the Medicaid agency during Stages I and II. As these "high-user" beneficiaries join full-risk health plans, the foundation of the fee-for-service operation begins to give way. The agency reaches a breakthrough point that calls for far-reaching changes in its internal organization and in its use of agency staff.

CHALLENGES AND RESPONSES

Our review of 10 State Medicaid agencies revealed 5 major internal challenges they face as they adapt to managed care. The challenges, in essence, are generic ones that any kind of organization is likely to face in making a fundamental shift in its products and modes of operation. In this section, we explain the challenges and the agencies's responses to them. In large part, our discussion of the responses offers further illustration of the challenges by revealing the obstacles confronted in the implementation process.[13]

Challenge #1: Establishing a Core Developmental Team

To chart the course, the Medicaid agencies must assemble a leadership core that is committed to the managed care mission, energized by the conceptual and operational challenges it creates, and determined to persevere in the midst of complexity and uncertainty. This core must extend beyond the level of politically appointed officials into the career staff of the agency.

The formative stage of managed care program design and implementation can extend over a number of years. It is a period of innovation requiring people at the helm who thrive in such environments. The feasibility and durability of the reforms are likely to be enhanced if the leadership team includes some individuals that have been part of the agency's career staff and that are well-steeped in the operational and policy landscape of the Medicaid program.

▸ **Each of the agencies has assembled a core of officials who are strongly committed to managed care reforms.**

In most of the Medicaid agencies we reviewed, there is a core managed care leadership that is highly committed to managed care reforms.[14] The members of the team tend to see these reforms as vital not only for containing costs, but also for improving the access of beneficiaries to good quality care. They are curious about the dynamics of the health care marketplace and about how the agency can best relate to it. They seek to act as prudent purchasers of health care on behalf of their customers -- the Medicaid beneficiaries.

The core staff come almost entirely from the fee-for-service sector of the agency or from other State agencies. Staff in the Medicaid agency tend to see the managed care office as the place where the action is and as a good place to get ahead. Or at least to avoid losing ground. As one State official noted: "Everyone knows that the office of managed care will be the last place to suffer any downsizing."

▸ **For the most part, the core staff work in isolation from the fee-for-service part of the Medicaid agency.**

The fast pace and the frequent crises that characterize managed care offices may contribute to their isolation from staff operating the routine fee-for-service operations. A comment by one managed care official echoed by many of his counterparts was: "we are an island unto ourselves." Many managers indicated to us that such separation is necessary during the early developmental phases of managed care, but can become dysfunctional if still applicable as managed care becomes more established. For instance, in one agency, managers informed us that with fee-for-service and managed care staffs speaking very different languages, the job of budgeting had become very difficult.

Challenge #2: Acquiring the Necessary Knowledge and Skills

As Medicaid agencies become increasingly committed to managed care, they must have ready access to knowledge bases and skills that are different than those typically held by their fee-for-service staffs. They become particularly dependent on expertise in negotiating contracts with health plans, in developing and carrying out quality assurance systems, and in relating to stakeholder groups.

In the early period, developmental, planning, and public relations capacities are of great importance. Later, once managed care becomes more mainstream, monitoring and evaluation capacities become much more significant. Throughout, however, the agencies find themselves with a greater need for staff with broad backgrounds who can understand health care delivery systems and who can fit the pieces together.

▸ **In developing their managed care efforts, the agencies have been able to tap into considerable expertise.**

Most of the agencies have relied heavily upon consultants, both for technical assistance on matters such as ratesetting, contract development, and computer modification, and for ongoing service functions, such as pre-enrollment education and actual beneficiary enrollment. In Rhode Island, the Medicaid agency has turned to a consultant firm to carry out a central, ongoing leadership role for its overall managed care effort.

The other State agencies we reviewed have relied more fully on their own staffs to provide direction. In Massachusetts, the agency built up a core staff by bringing in many individuals experienced in the managed care industry, either directly with health plans or with employers purchasing services from the plans. This, however, has been the exception. In most of the agencies, few if any staff have industry experience. Yet, mainly through on-the-job training and trial-by-fire, many of them have gained considerable know-how about managed care. To date, more of that know-how seems to relate to purchasing and contract development than to health plan oversight. But that is changing as the number of Medicaid enrollees in full-risk health plans continues to increase.

▸ **In building up and maintaining their own staff expertise, the agencies face significant constraints that emerge from outmoded State personnel systems and from minimal investments in staff development.**

Medicaid agency managers routinely complained to us about State personnel systems that make it enormously difficult for them to recruit people with experience in the managed care industry, to rotate agency staff among different positions, and to give sufficient rewards based on performance.[15] Every bit as much, they expressed concerns about the meager resources available for staff development. Rarely, for instance, could they even send an employee to an out-of-State conference.

California's "Broken" Civil Service System

"California's Civil Service System is broken. Today, there are no rewards for outstanding performance, and no consequences for poor performance. It is difficult to hire outstanding applicants, and it is difficult to fire the 'bad apples.' Salary is based on longevity, not productivity. In a rapidly changing technological environment, workers lack adequate training. It is a topsy-turvy world characterized by perverse incentives. It must be changed."

(From "Competitive Government: A Plan for Less Bureaucracy, More Results, Office of the Governor," April 1996.)

Over time, many officials stressed, the consequences of this situation become troubling. Capable, experienced staff leave. Some career staff end up in roles for which they are ill-suited. Some become too dependent for day-to-day learning on the staff of the health plans which have contracts with the Medicaid agency. A number of plan representatives reminded us that they regularly educate Medicaid staff about how managed care works.

Challenge: #3: Instilling a New Organizational Mission and Culture

For Medicaid agency staff accustomed to the fee-for-service routines, managed care portends fundamental change. It means that they must reorient themselves to an agency that is beginning to focus on beneficiaries rather than on providers and to define itself more as a health care purchaser than a bill payer. Agency leadership must find ways of enabling staff throughout the organization to make this transition.

Toward the later part of Stage I and into Stage II, it becomes increasingly apparent that managed care represents more than marginal change affecting one sector of the Medicaid agency. In fact, it looms as a paradigm shift, recasting the role of the Medicaid agency and most of its workforce. A before and after analysis prepared by the Minnesota Department of Human Services reveals the extent of this shift (see table 2).

TABLE 2
PARADIGM SHIFT FOR MINNESOTA DEPARTMENT OF HUMAN SERVICES

Components	Old Approach	New Approach
Agency role	Service agency	Service agency for non-health care/purchaser for health care
Management approach	Mix of assistance, collaboration, regulatory, and contractual	Business contractual relations for health care purchasing; collaborative approach for non-health care
Areas of responsibility	Individual programs	Population based rather than program based
Approaches to responsibility	Regulation	Flexible strategies for contracting for specific results
Goal	Operating programs	Assuring value: access, accountability, and affordability
Purchasing strategy	Reimbursement of individual services	Managed competition
Eligibles	Recipients	Enrollees
Provider relationships	Individual service providers	Care delivery network
Managed care contractors	HMOs	Managed network care delivery systems
Accountability	State and provider	Individual, state, care delivery networks
Quality	Regulatory approach	Quality improvement systematic
Purchasing role	Through counties and tribes; directly with individual providers	Joint purchasing strategies

▸ **For the most part, the agencies have not yet addressed this challenge.**

The move toward managed care does not occur as surely and orderly as our sequential schema may suggest. Medicaid agencies carrying out PCCM and/or full-risk managed care efforts confront ongoing complexities that concern policy design, operational detail, and political controversy. These realities almost invariably reinforce a short-term perspective, with little time for cultivating strategies that will instill a new mission and culture in a successfully transformed agency.

In Stage II the consequences of such inattention begin to mount. Staff who are not yet part of the managed care effort become more concerned about what the effort will mean for them. For instance, with many third-party-liability (TPL) functions being passed on to health plans for their Medicaid enrollees, TPL staff wonder how their jobs will be affected. Will their skills be transferrable? Indeed, will their jobs be threatened? Left unanswered, such questions jeopardize staff morale and productivity.[16]

The consequences can also be worrisome for agency staff who have already been given managed care responsibilities. Some of them remain uneasy in their new situations, uncertain about the implications or merits of the paradigm shift noted above. Some find their instinctive way of viewing the Medicaid program remains rooted in the traditional fee-for-service program. They may find it difficult, for instance, to adjust to oversight roles that focus on the dangers of underutilization in managed care arrangements after years of contending with the overutilization biases of fee-for-service systems.

▸ **Some agencies have undertaken what appear to be promising approaches to encourage staff acceptance of managed care.**

In various ways, some agencies are seeking to deemphasize the dichotomy between managed care and fee-for-service and to foster integrative perspectives that cut across these sectors. One such approach is to explain the agency's new mission in such terms. For instance, the Ohio agency stresses its aim to maximize its leverage in the marketplace and to get the best possible deal with respect to cost, quality, and access. It poses this overarching value-purchasing goal as one pertinent to both the fee-for-service and managed care sectors and to hybrid initiatives involving both.

Another depolarizing approach is to organize work units in ways that integrate roles across the two sectors. The Minnesota agency, for example, has developed what it terms "cross-cluster project teams" responsible for basic Medicaid benefits, continuing care for special populations, health care purchasing, and quality improvement. The Missouri agency has placed fee-for-service and managed care staff together in multiple units, with the intent to foster staff buy-in and to change the agency's mission.

Some agencies are also furthering staff buy-in by hiring consultants to help identify staff concerns and means of responding to those concerns. The Oregon agency, now in Stage III, used consultants to help it work on morale, relational and teamwork issues as it expanded the scope of managed care. More recently, the Massachusetts[17] and Missouri[18] agencies have been doing the same.

Challenge #4: Redeploying Staff

Continued movement toward Stage III leads to a point where the fee-for-service workloads diminish and the agencies must redeploy significant numbers of the fee-for-service staff into managed care roles. Most of these individuals will have little preparation for their new roles.

In each State except Oregon, the fee-for-service sector still accounts for the great majority of Medicaid agency staff. In those States, agency leadership faces the enormous challenge of redeploying much of that staff into managed care while maintaining morale and operating both fee-for-service and managed care programs.[19]

▸ **Thus far, most of the agencies have not reached the point of redeploying major segments of their fee-for-service staff. In fact, many report that their staffing needs for managed care have increased faster than those for fee-for-service have declined.**

The fee-for-service sector caseload includes the sickest individuals generating the most claims. As long as most of them remain in this sector, they will continue to call for a disproportionately large share of agency staff support. This slows the pace at which the Medicaid agencies can phase down fee-for-service operations. So too do other largely unavoidable factors. One is what some claims processing staff describe as the "trailing effect," whereby fee-for-service claims for beneficiary services come in as much as 1 year after beneficiaries have shifted to managed care. Another is a temporary, but sometimes significant increase in inquiries to provider relations staff from providers seeking clarifications about the implications of new managed care policies.[20]

In some States, continued pressures on the fee-for-service staffs appear to sustain a separation between fee-for-service and managed care staffs. One agency manager noted that those pressures prevent the agency from shifting staff as it would like and make it hard for the agency to come together. In other States, the agencies have developed explicit policies of gradually incorporating some managed care responsibilities into the work of fee-for-service staff. A manager in an agency that has taken this approach said that it has enabled more staff to be supervised by some in their own discipline and, as such, has lead to a greater overall commitment to managed care.

▸ **In many of the agencies, the move toward major staff redeployment is imminent. Both internally and externally, pressures toward this end are mounting.**

One agency director said: "We are now at the point of making decisions of where to drop off fee-for-service pieces." Agency managers in other States made the same point. In a number of States, the fee-for-service claims volume has just recently begun to decline. This suggests some freeing up of fee-for-service staff. In some States, most especially California, legislatures are becoming increasingly aware of this development and beginning to look for associated budget savings.[21]

In one traditional fee-for-service sphere--surveillance and utilization review (SURS)--the momentum toward staff redeployment appears to be gaining particular strength. In a number of the agencies, many SURS staff have been refocusing on quality improvement functions as opposed to the traditional fraud and abuse investigations. In some cases this has entailed transfers to new organizational units; in others, a realignment within existing units.

Pressing for Administrative Savings

In reviewing the Governor's Medicaid budget for Fiscal Year 96/97 budget, the California Legislative Analyst's Office recommended eliminating 48 field office positions and reducing the claims processing contract. These actions, it held, could save $3.3 million, and were justified because managed care expansion was contributing to a declining fee-for-service workload.

The Governor's Office successfully maintained that such reductions were premature for that year. However, in its Fiscal Year 97/98 budget, it has proposed a reduction of $3.1 million and 60 positions in Medicaid prior authorization staff because of the advance of managed care.

Challenge #5: Avoiding a Fee-For-Service Meltdown

In the shadow of managed care, fee-for-service often becomes viewed as the residual sector responsible for an outmoded product line. Yet, even into Stage III, it is likely to account for a majority of Medicaid expenditures and staff. Medicaid agencies must find ways of maintaining the effectiveness of this product line as they diminish its scope and continue to expand managed care.

One Medicaid agency manager framed the challenge well by asking these questions: "How do you manage two systems concurrently? You have people on both ends and people floating in the middle. How do you get people to change and get people who understand and have skills for both systems?"[22]

▸ **Less innovation. Lower morale. Slower responses. These and other danger signs are becoming increasingly apparent in the fee-for-service sector of the agencies.**

Managers in most of the agencies we contacted indicated that the heightened attention being given to full-risk managed care was having some dysfunctional consequences on traditional fee-for-service operations. Although they did not see these consequences of great concern at this point, they believed that they could intensify as the move toward managed care accelerated. They indicated that the undesirable effects tend to be subtle and gradual, stemming from reduced program innovation and initiative on the fee-for-service side. Particularly common is reduced access to agency programming staff, who tend to be focused on managed care efforts and less available to help with efforts such as the development of new payment methodologies for various fee-for-service functions.

This situation, as one manager noted, could well require a greater tolerance for errors in the fee-for-service sector. For instance, reduced provider education efforts by provider relations staff could (and some say do) contribute to a higher rate of erroneous provider claims which end up being denied.

In table 3, we address the effects of managed care on six selected fee-for-service functions. Our observations focus on the big picture that emerges when considering the 10 States we reviewed. In various ways and to varying degrees, of course, each State's own situation varies from the synthesis observations we offer.

TABLE 3
EFFECT OF MANAGED CARE ON TRADITIONAL FEE-FOR-SERVICE FUNCTIONS

Function	Extent of Effect	Nature of Effect
Third Party Liability (TPL)	Moderate to Substantial	TPL role typically passed on to health plans. Leading to reduction in State agency TPL staffs and loss of agency expertise. Widespread concerns that health plan dollar recovery results will be less than those achieved by the agency.
Surveillance and Utilization Review Systems (SURS)	Moderate to Substantial.	Reductions in SURS exceptions and fee-for-service SURS staff. Refocusing on quality measurement and targeted studies. Decreased support for fee-for-service investigations. Little staff experience with managed care investigations.
Drug Utilization Review (DUR)	Moderate to Substantial.	Most States give DUR role to health plans. DUR staff have little connection with agency managed care staffs or with health plan DUR efforts. Most prescription drug expenditures still accounted for by aged and disabled fee-for-service population.
Provider Relations	Moderate.	Transition process triggers increase in inquiries. Signs in some States of dysfunctional effects such as longer response times, less attention to proactive provider education, and even an undermining of staff service ethic.
Claims Processing	Moderate.	Programming changes to accommodate managed care enrollments, payments, and encounter data. Five to 10 percent reduction in claims volume in some States. Some slippage in fee-for-service housekeeping tasks, such as correcting errors.
Prior Authorization	Minor.	Minimal signs of drop-off in workload as aged, blind, and disabled cases continue to sustain prior authorization efforts. But in a few States discussions already beginning about how to plan for substantial staffing reductions in next 2 to 3 years.

Our review reveals that the danger signs are particularly notable for three traditional fee-for-service functions. The first, and perhaps most pressing danger involves, the delegation of third-party-liability (TPL) responsibilities to the health plans.[23] These responsibilities involve identifying and obtaining payments from any other sources of insurance or coverage held by Medicaid beneficiaries. This is a process in which many Medicaid agencies have become quite adept and have used to achieve significant savings.[24] Most health plans, in contrast, have little experience with TPL tracking and recovery techniques. As long as prior fee-for-service TPL savings are reflected in capitated rates, the potential financial risks to Medicaid are contained. The enduring challenge will be to ensure that capitated arrangements do not erode the incentives and expertise needed to maximize TPL recoveries.[25]

The second concern centers around signs of a diminishing focus on fraud and abuse investigations in the fee-for-service sector at a time when that sector is still the dominant one in the great majority of State Medicaid agencies. This concern is reinforced by a recent Office of Inspector General report documenting a decline in the number of suspected fraud referrals to State Medicaid Fraud Control Units.[26] As important as it is to gear up to handle the new oversight responsibilities associated with managed care, a reduced scrutiny at this point on the fee-for-service side would seem to be an unacceptable price.

Finally, delegating DUR responsibilities to health plans raises concerns about how fully DUR programs are being used to oversee the adequacy of drug therapy regimes of Medicaid managed care enrollees. In accord with the requirements of the Omnibus Budget Reconciliation Act of 1990, State Medicaid agencies have developed DUR programs geared to their fee-for-service beneficiaries.[27] But, as we stressed in a prior report addressing the lessons learned by those programs, the infrastructure and insights they developed become increasingly irrelevant as beneficiaries are enrolled in health plans.[28] Thus far, the agencies report that they have little information about the thrust or effects of the plans' own DUR efforts. Adding to our sense of concern are findings in one of our more recent reports that most health plans contract with pharmaceutical benefit management companies to manage their prescription drug benefits and conduct only minimal oversight of the performance of these firms.[29]

These concerns, we emphasize, are put forth as danger signs - as early alerts to what could emerge as significant problems if not adequately addressed. At the same time, we recognize that with proper guidance fee-for-service management can actually be strengthened as managed care expands. To some degree, this may in fact be happening in some States, especially those with large PCCM programs.[30]

▸ **Notwithstanding the danger signs, the fee-for-service sector of Medicaid agencies is not moribund. Within it are some creative stirrings that could contribute significantly to reinvigorated Medicaid agencies in the years ahead.**

Particularly promising are those initiatives that seek to introduce a value purchasing approach to that sector. The Ohio agency, for example, has engaged in selective contracting for home and community based services and has negotiated a contract with a single provider for vision care services. Other agencies have taken similar approaches, which represent a significant contrast from the traditional bill-payer orientation of Medicaid agencies, but yet are not capitated managed care.

Many agencies are also actively involved in managing the care of certain high-cost beneficiaries who continue to be served within the fee-for-service sector. For instance, the California agency has been carrying out a medical case management program directed to patients who have had multiple hospital admissions and/or complex treatments. Under the program, agency nurses work with the providers and patients to facilitate care in home settings and to avert preventable hospital readmissions. For Fiscal Year 1994-95, the agency documented savings of $11.2 million for 2,349 cases.[31] The State legislature was impressed enough to authorize funding for 46 new positions to support the program; this at a time when the agency's capitated managed care program was moving full speed ahead.

Finally, within individual fee-for-service sectors, one can find some efforts to minimize the adverse effects associated with downsizing. Striking in this regard is the Oregon agency's initiative in using prisoners to respond to basic telephone inquiries by providers and beneficiaries. Facilitated by a Statewide referendum that called for prisoners to be engaged in training or employment, this initiative has enabled a downsized provider relations staff to focus on more complex inquiries and to reduce its backlog of billing exceptions.

RETOOLING AS AN ISSUE

Retooling of Medicaid agencies for managed care has been a low priority issue.

This has been true for Medicaid agencies' leadership, the State legislatures, and the Health Care Financing Administration of the U.S. Department of Health and Human Services. In each of these settings, the focus of those concerned with managed care is on the substance of the effort as it affects providers, beneficiaries, and taxpayers. In the States we reviewed, even in those where managed care is well advanced, the emphasis on program design and implementation has been nearly all encompassing. Further, although important work has been done in developing conceptual frameworks, overall missions, and long-term plans, agency managers find themselves compelled to concentrate on near-term actions, often in a reactive rather than proactive mode. "Long-term around here," said one agency manager, "is about 2 months."

In this environment, agency leadership from time to time has given substantial attention to reorganizations intended to position the agency more effectively for the transition to managed care. But the thorny particulars of reorienting, retraining, and redeploying staff for new roles typically have remained on the backburner. And State legislatures to this point have expressed little interest in these particulars.

The Health Care Financing Administration (HCFA) has indicated some concern about these administrative issues. Its Medicaid monitoring guide for regional office officials raises some general questions that bear on the Medicaid agency's organizational readiness to carry out a managed care program. More notably, in its guide intended to help HCFA reviewers assess the readiness of States to carry out Section 1115 waivers, it has a section on State administration that poses some pertinent "retooling" questions to address. It asks for instance: "..what problems does the State foresee in running two parallel Medicaid programs? How will the two programs be coordinated?" It also asks: "Have key staff been hired and trained....?"

These and a few other such questions posed by HCFA address important issues concerning how Medicaid agencies equip their organizations. At times, they have led to communications with State officials about the adequacy of administrative resources being devoted in support of managed care efforts. But they typically are overshadowed by hundreds of other questions and communications focusing on the programmatic content and processes of managed care.

RECOMMENDATIONS

Our review indicates that during Stage I and even well into Stage II, State Medicaid agencies have not found it necessary to give major attention to the retooling challenges addressed in this report. In part, this is because the agencies' managed care initiatives have not yet had a substantial effect on their fee-for-service operations and staff. It is also because they have been able to assemble a core of talented staff who have been fast learners and have assumed the lion's share of design and early implementation responsibilities. Some of the agencies have been more aggressive than others in tackling and anticipating the internal organizational changes that will be necessary as they increase their commitment to managed care, but even in these cases, the efforts are more appropriately characterized as backburner rather than frontburner matters.

As Medicaid agencies approach and enter Stage III, this situation will have to change. As the decline in fee-for-service workloads accelerates, agency managers will be compelled to give high priority to how they redeploy most of their workforce into very different roles, orient them to a new mission, train them to develop new skills, and at the same time make certain that remaining fee-for-service operations continue to perform adequately. In the midst of all this, some, and perhaps most, of the agencies will also have to engage in significant downsizing of their staffs. A transformed agency focused on full-risk managed care and prudent purchasing typically will not require the staffing levels of traditional Medicaid agencies.

This transition presents major opportunities. The inevitable disruption provides management with a chance to reengineer their agencies in ways that enhance their overall productivity. In fact, given the scope of the internal changes necessary, Medicaid agencies could well serve as pioneers for workforce reforms for all of State government. Moving in this direction, however, will call for substantial support from both State governors and State legislatures. In particular, they would have to be willing to allow for and even urge changes in State civil service systems that now impede agency efforts to make most effective use of their human resources.

At the same time, the transition presents major dangers, particularly if the agencies are not adequately prepared for them. In the fee-for-service sector, lower levels of priority, innovation, and morale could erode service to beneficiaries and providers still dependent on that sector, and could weaken important oversight activities. In the expanded managed care sector, poor staff training, motivation, and organization could undermine the transition to capitated health care arrangements that State government is counting heavily upon to help contain Medicaid costs and improve the beneficiaries' access to good quality services.

The lead role here is that of the States. But given the partnership nature of the Medicaid program, the Federal government and State governments should work cooperatively in finding effective ways of dealing with these challenges. Toward that end, we direct the following recommendations to the Health Care Financing Administration:

The HCFA should provide forums to help State Medicaid managers take advantage of the opportunities managed care presents for retooling their agencies and to minimize the associated dangers.

These forums could be convened at the national level, through the establishment of a work group or technical advisory group, as well as at regional levels, through the efforts of regional offices. State environments are too varied to expect that the development of a set of explicit national guidelines would be feasible. However, written analyses and discussions of lessons learned and promising approaches identified by State officials themselves could be quite useful. It could be particularly useful to tap into the experiences of those States where Medicaid managed care penetration is well advanced.

This kind of activity is especially important in view of our finding that State officials rarely get to attend conferences to become exposed to lessons learned by other States in moving from fee-for-service to managed care environments.

The HCFA should revise its review and monitoring protocols so that they devote greater attention to how State Medicaid agencies are handling the organizational challenges associated with expanded managed care.

These issues are too complex and too rooted in the distinctive characteristics of State political and organizational cultures to be conducive to checkmark certifications by federal reviewers. But in the course of its efforts to monitor State agency managed care initiatives, to review Section 1915 and 1115 waiver requests, and, most especially, to evaluate Section 1115 research and demonstration projects, HCFA (and its contractors) should incorporate greater discussion, inquiry, and assessment of retooling issues into its reviews. For agencies approaching and into Stage II, these reviews should devote particular emphasis to agency plans and activities involving the redeployment of fee-for-service staff. At the least, this process could help generate more attention to these issues at the State level. Beyond that, it could well yield insights that are helpful to State agency managers.

The HCFA, in its ongoing reviews of State Medicaid agencies, should scrutinize possible adverse effects of managed care expansion on the performance of established fee-for-service functions.

In these reviews, HCFA should give special attention to possible danger signs we noted concerning third-party-liability, surveillance and utilization review subsystems, and drug utilization review.

With respect to third-party-liability (TPL), HCFA has been well aware of the dangers that we note. For some time it has been working with State representatives and the American Public Welfare Association through a technical assistance group addressing the dangers and how to address them. Most recently, these efforts have led to (1) the design and distribution of a survey to obtain up-to-date information on how States are handling TPL for beneficiaries in managed care, (2) the restructuring of State data reporting requirements to ensure that States report to HCFA third-party collections made by health plans, and (3) joint agreement that the American Public Welfare Association will prepare for the State Medicaid agencies a technical assistance piece that will offer guidance on how to incorporate TPL responsibilities in contracts with health plans.[32] These are constructive initiatives. Our recommendation is intended to reinforce their significance and to encourage State Medicaid agency leadership to be fully alert to the most cost-effective ways of pursuing third-party-liability in managed care environments.

In regard to surveillance and utilization review subsystems (SURS), HCFA's Program Integrity Group has been undertaking initiatives that could help improve the effectiveness of State SURS units.[33] In response to the recent OIG report on these units, for instance, HCFA noted that it plans for these units to be users of its recently developed fraud investigation database. However, the intent of this initiative would be undermined if the remaining fee-for-service SURS units in the States lack sufficient staff resources or expertise to take full advantage of this database. This matter may warrant some attention by the Program Integrity Group.

For drug utilization review, finally, State Medicaid agencies and HCFA look to the collection and analysis of encounter data from plans as a way of overseeing their performance on drug management issues and minimizing the kind of danger we note in this report. However, with such efforts being in their very early stages, additional measures could be warranted. In that context, HCFA could work with the Medicaid agencies to identify ways of using the health plan contract as a vehicle for holding plans more fully accountable for how they manage drug therapies. These could involve the incorporation into the contracts of: (1) performance measures concerning prescription drugs that are set forth in the Health Plan Employer Data Information Set developed by the National Committee for Quality Assurance and (2) specific assurances that plans would obtain in their subcontracts with PBMs.[34] It could also involve, as we have noted in a previous report, increased State review of pharmacy practice in its on-site monitoring of the plans.

COMMENTS ON THE DRAFT REPORT

We solicited and received comments on the draft report from the Health Care Financing Administration, the Acting Assistant Secretary for Health (ASH), and the Assistant Secretary for Planning and Evaluation (ASPE). The ASPE concurred without elaboration. The HCFA and ASH comments appear in full in appendix B. Below we summarize them and offer our response in italics.

The HCFA concurred with our first two recommendations. It reinforced the importance of using existing mechanisms to help States learn from one another as they move from fee-for-service to managed care arrangements. It also agreed with the importance of reviewing and revising HCFA monitoring protocols so that they are sufficiently sensitive to the organizational challenges associated with expanded managed care.

With respect to our third recommendation calling for the State Medicaid agencies to scrutinize possible adverse effects of managed care expansion on the performance of established fee-for-service functions, HCFA offered a partial concurrence. It noted that actions taken in response to the first two recommendations could alleviate the need for such scrutiny and that HCFA, as our report indicates, is already doing a good deal to monitor possible adverse effects.

In line with the above comment, HCFA suggested that our reference to "danger signs" in the fee-for-service sector be changed to "concerns." It also suggested that the States discussed in the report be given the opportunity to comment on it.

We considered HCFA's suggestion on characterizing the possible problems in the fee-for-service sector as "concerns" rather than "danger signs." We decided to retain the latter term because it more accurately reflected what we heard and observed in the study States. At the same time, as we note in the report, we present the danger signs as early alerts that could emerge as significant problems if not adequately addressed.

Concerning HCFA's other comment about obtaining feedback from the States reviewed, we have received considerable comment from them during the course of framing our findings and recommendations. We are distributing the report widely among the States, and, as is our custom, will include with it a user feedback form inviting further comment.

Finally, the Acting Assistant Secretary of Health did not comment on specific findings or recommendations in the report, but did offer four suggestions intended to enhance the transition process to Medicaid managed care. They are helpful suggestions that warrant consideration by the States and HCFA. They concern the involvement of the State health departments in the managed care process, the need for broad stakeholder involvement in the process, the need to strengthen the integration of public health concerns into the change process, and the importance of strengthening compliance, monitoring, and evaluation at the State level.

APPENDIX A

BACKGROUND ON MEDICAID MANAGED CARE

Medicaid Expansion into Managed Care Programs

Over the past 15 years, States have increasingly used managed care to provide medical services for Medicaid beneficiaries. This trend has accelerated in the past few years: in 1991, 2.7 million Medicaid beneficiaries were enrolled in managed care, by 1993, that number grew to 4.8 million, and in 1996, 13 million. As of June 1996, 39 percent of all Medicaid beneficiaries were enrolled in some kind of managed care arrangement.

To date, States have primarily enrolled adults and children in low-income families into managed care, whereas aged or disabled beneficiaries remain under fee-for-service systems. By 1996, over 500 managed care organizations were providing services to 13 million Medicaid beneficiaries.

The movement to enroll Medicaid beneficiaries in managed care began in earnest in the early 1980s, as States experienced significant fiscal pressures due to rising Medicaid costs. While States viewed managed care as a way to contain Medicaid costs, they were constrained by Federal standards required for Medicaid enrollment in managed care.

In response to mounting concerns, Congress allowed States greater flexibility to deviate from those standards through amendments to the 1981 Omnibus Budget Reconciliation Act.[35] For example, the amendments allow States to pursue freedom-of-choice waivers (under section 1915 of the Social Security Act) that release them from certain Federal provisions, such as the free-choice-of-provider provision. To date, 42 States have freedom-of-choice waivers.

States also can receive research and demonstration waivers under section 1115 of the Social Security Act. Since 1992, many States have aggressively pursued such waivers. States implementing or pursuing 1115 waivers often extend, as a part of their demonstration, insurance benefits to those not otherwise eligible for Medicaid, such as the working poor and their families. As of this writing, HCFA has approved 18 research and demonstration waivers. Of those, 12 States have implemented their programs, 5 are pending implementation, and one has no plans to implement.[36] The HCFA is currently reviewing nine States' applications.[37]

Defining Managed Care

Although managed care organizations vary, they generally feature a focus on primary, preventive health care and care coordination. That focus is believed to improve care and access for enrollees. It is also thought to promote cost containment, thus slowing the rate of increase in health care spending.

The managed care organizations enrolling Medicaid beneficiaries can generally be defined as fitting into one of two basic types: health maintenance organizations and fee-for-service primary care case management (PCCM) programs. Both types feature coordinated care. But each carries a different level of financial risk. Health maintenance organizations (hereafter referred to as health plans or plans) are full-risk plans that contract with Medicaid for a fixed fee per person and provide comprehensive services.[38] PCCM programs comprise providers, usually primary care physicians, willing to serve as gatekeepers and take responsibility for approving and coordinating enrollees' care. Medicaid pays PCCM providers on a fee-for-service basis, but they receive a case management fee to cover their added responsibilities. Thus PCCM providers are at no financial risk.

Some agencies also contract with plans separately for certain aspects of care, such as mental health, substance abuse, and dental care. The arrangements for these "carve-outs" vary in terms of the services included and the level of financial risk the plan assumes.

APPENDIX B

COMPLETE COMMENTS ON DRAFT REPORT

In this appendix, we present in full the comments of the Health Care Financing Administration and the Acting Assistant Secretary for Health.

DATE: JUN 27 1997

TO: June Gibbs Brown
Inspector General

FROM: Bruce C. Vladeck
Administrator

SUBJECT: Office of Inspector General (OIG) Draft Report: "Retooling Medicaid Agencies for Managed Care," (OEI-01-95-00260)

We reviewed the above-referenced report that identifies major organizational challenges state Medicaid agencies face as they shift their focus to managed care.

Our detailed comments on the report recommendations are attached for your consideration. Thank you for the opportunity to review and comment on this report.

Attachment

Comments of the Health Care Financing Administration (HCFA) on Office of Inspector General (OIG) Draft Report: "Retooling Medicaid Agencies for Managed Care," (OEI-01-95-00260)

OIG Recommendation 1

HCFA should provide forums to help state Medicaid managers take advantage of the opportunities managed care presents for retooling their agencies and to minimize the associated dangers.

HCFA Response

We concur. HCFA, in conjunction with the American Public Welfare Association (APWA), already has in place several mechanisms that provide states an opportunity to exchange lessons learned. As a result of this report, HCFA is now cognizant of the need to determine those states that have the greatest experience in moving from fee-for-service to managed care environments (identified as Stage III in the report) and to encourage those States to share their experiences with less advanced states through these existing forums.

States may learn much about what works and what does not from states such as Oregon and California. If HCFA Regional Offices were to develop local work groups on managed care issues, most states would be able to handle issues unique to managed care before the Medicaid managed care population climbs to over 50 percent nationwide.

OIG Recommendation 2

HCFA should revise its review and monitoring protocols so they devote greater attention to how state Medicaid agencies are handling the organizational challenges associated with expanded managed care.

HCFA Response

We concur. The OIG report acknowledges that the current readiness review guide for section 1115 waivers contains a section on State administration with pertinent retooling questions. We anticipate the ongoing review and revision of all of the monitoring protocols will be enhanced through the consolidation of various areas of expertise in the imminent HCFA reorganization, which will bring together the components responsible for the review and approval of 1915(b) and 1115 waivers.

OIG Recommendation 3

HCFA, in its ongoing reviews of state Medicaid agencies, should scrutinize possible adverse effects of managed care expansion on the performance of established fee-for-service functions.

HCFA Response

We partially concur. HCFA is concerned about the impact of managed care on the health systems within a state. Hopefully, the first two report recommendations would, however, alleviate the need for heavy scrutinizing of those effects. Also, as the report points out, HCFA and states are already doing a considerable amount of monitoring. HCFA and the APWA have a technical advisory group addressing third-party liability. The Program Integrity Group is monitoring Surveillance and Utilization Review Subsystems (SURS). And, HCFA uses encounter data to review drug utilization. While RO forums should address these concerns, it is the direction of this Administration to set guidelines, but not heavily regulate state activities. However, past state performance in these areas in a managed care setting could be factors in approving section 1115 waivers and other programs.

Additional Comments

1. We suggest the States that are discussed in the report be given the opportunity to comment on the draft report.

2. Rather than referencing danger signs concerning third party liability, SURS, and drug utilization review, we suggest referring to these items as concerns.

DEPARTMENT OF HEALTH AND HUMAN SERVICES Office of the Secretary

Assistant Secretary for Health
Office of Public Health and Science
Washington D.C. 20201

JUL 15 1997

TO: June Gibbs Brown
Office of Inspector General

FROM: Acting Assistant Secretary for Health

SUBJECT: Draft: Retooling Medicaid Agencies for Managed Care OEI-01-95-00260

Thank you for the opportunity to comment on your draft report: "Retooling Medicaid Agencies for Managed Care." This issue continues to be extremely important as more states submit and receive approval of their 1115 Demonstration waivers. Comments and recommendations relative to enhancing state Medicaid agencies preparedness for conversion to managed care are attached.

They center on four areas which states could focus on to enchance the transition process to Medicaid Managed Care:.

1. Broad and explicit state health department involvement at all stages of the 1115 process;
2. The need for broader stakeholder involvement at the state and local levels;
3. The need to strengthen the integration of public health concerns into the overall 1115 waiver process, with particular emphasis on implementation; and
4. Strengthening compliance, monitoring and evaluation at the state level.

I appreciate the opportunity to provide you with our input and trust that you will consider these recommendations. Once again, thank you for soliciting our input.

John M. Eisenberg, M.D.

Attachment

U.S. Public Health Service

1. Broad and explicit state health department involvement at all stages of the 1115 process.

   A. Assuring the Integration of all State Deparmental Resources for Transition to Medicaid Managed Care in order to ensure greater commitment on the part of state Medicaid staff to the conversion to managed care, staff needs to be fully integrated into a collaborative process by which planning of the pre-application and design phase takes place. Staff also should be involved during the approval, implementation and monitoring and evaluation phases, again to ensure an understanding of the goals to be achieved and a commitment to facilitating the transition.
   The appropriate state agencies, including public health, should be invited to provide the necessary resources for adequate technical assistance to the state Medicaid agency to assist in anticipating potential problem areas.

   B. Reconciling Conflicting Policies between State Departmental Discretionary Programs and the New Medicaid System
   Programmatic authority for health care services to vulnerable populations (persons with HIV/AIDS, minority populations, and persons with mental health and substance abuse problems) historically have been a central mission of PHS agencies, such as Ryan White CARE Act Title I and II funds, Maternal Child Health Block grants, Mental Health/Substance Abuse Block grants and so on. The restructuring of the Medicaid delivery system inherent in the 1115 waiver program may place many of these federally funded programs in jeopardy due to the loss of Medicaid reimbursement dollars. Other areas where this may be problematic are Federally Qualified Health Centers, and mental health and substance abuse disorders. Due to these potential conflicts and ramifications for much needed programs, the State Department of Health should assess the impact of its waiver proposal on their federally funded programs that may be working at cross purposes with their existing Medicaid program. The state should identify policy options targeted toward specific programs that may need assistance during crucial transition periods in to Medicaid managed care, for example providing transitional financial support to a program during the phase-in of Medicaid managed care.

2. Stakeholder Involvement in the Development and Implementation of Waivers.

   State Medicaid agencies need to involve public health agencies, social service agencies and other key stakeholders, such as non-governmental organizations, consumer groups and family members, patient advocacy groups, providers, and any other relevant and family members, patient advocacy groups, providers, and any other relevant stakeholders, throughout the waiver process but especially at the early stages of the development of 1115 Demonstration waivers.

This requires active participation of these agencies and groups during the planning process to assist in anticipating potential issues that will emerge when designing a successful transition of Medicaid beneficiaries into managed care. States should strengthen their requirements for consultation that would help bring relevant expertise and perspectives to the planning and development process of Medicaid 1115 waivers land provide evidence in their applications that such a process was conducted.

Integration of Public Health Functions and Managed Care

To ensure that the transition to Medicaid managed care addresses the needs of the beneficiary population essential public health functions must be maintained and supported via the transition. Public health agencies have been challenged to provide individual and community-based health services and interventions for disadvantaged populations. For example, community interventions that alter the environment by either changing health-related behaviors or reducing the risk of causing a health problem. Many have relied on Medicaid revenue from personal health services to support vital population overhead public health functions like disease surveillance, food safety and so on. With the rapid movement of Medicaid beneficiaries into managed care, this population's personal health services needs will be met within the new delivery system, while the community/core public health functions will remain with public health departments. Because Medicaid funds have been important revenue sources to public health agencies, their ability to track and intervene on behalf of community-based health issues may be compromised due to this loss of federal support. This jeopardizes the public health infrastructure supported by HRSA's MCH block grants and a variety of CDC grants to States. Thus, deliberate steps in the transition to Medicaid managed care should promote important collaborative public-private partnerships between state and local health agencies and managed care plans.

Compliance, Monitoring and Evaluation

To assess the quality of health care service delivery and to obtain baseline information compliance with the special terms and conditions negotiated between the state and HCFA, monitoring of compliance and evaluation activities are essential. A state working group, which draws on the expert knowledge of individuals and organizations involved in the assessment of health services among varied patient groups would help identify the areas that warrant closer scrutiny. In addition, a working group could examine opportunities for use of some standard data sets across all waivers and develop mechanism to permit active involvement of appropriate state agencies to participate in reviewing the proposed evaluation designs..

APPENDIX C

ENDNOTES

1. See, for examples, General Accounting Office, *Medicaid: Data Improvements Needed to Help Manage Health Care Program* , (IMTEC-93-18), May 1993; General Accounting Office, *Medicaid: Experience with State Waivers to Promote Cost Control and Access to Care*, (T-HEHS-95-115), March 1995; Kaiser Commission on the Future of Medicaid, *Medicaid and Managed Care: Lessons from the Literature*, Washington, DC, March 1995. John K. Iglehart, "Health Policy Report: Medicaid and Managed Care," *New England Journal of Medicine* (322) 25, June 22, 1995, 1727-1731; Joel Schendler, "Implementing a Managed-Care System in a Fee-for-Service Environment," *W Memo*, vol.7, no.7, July 1995, pp. 29-31; Physician Payment Review Commission, *Annual Report to Congress, 1995*; General Accounting Office, "Medicaid Managed Care: More Competition and Oversight Would Improve California's Expansion Plan," (HEHS-95-87), April 1995; National Academy for State Health Policy, *Medicaid Managed Care: A Guide for States*, Portland, Maine, 1995; and Michael S. Sparer, *Medicaid Reform and the Limits of State Health Reform*, (Philadelphia: Temple University Press, 1996.

2. In this report, we use the term "organizational" challenges in reference to those internal issues affecting the productivity of the agency. They center around how agency management relates to agency staff and defines their missions, roles, and tasks. These challenges are of course related to, but yet distinct from those focusing on the design, implementation, and assessment of managed care efforts.

3. The National Academy for State Health Policy has given some attention to these challenges. See its chapter on administrative issues in *Medicaid Managed Care Guide: A Guide for States.*

4. Donna Checkett, "A State Medicaid Director on Medicaid Managed Care," *Health Affairs* 15 (3), Fall 1996, 172.

5. The States are California, Florida, Ohio, Massachusetts, Minnesota, Missouri, New York, Oregon, Rhode Island, and Utah. Our in-depth visits were to California, Minnesota, and Massachusetts.

6. Nowhere, it seems, has Medicaid managed care been ushered in more quickly than in Tennessee. See G. Girden Bonnyman, Jr., "Stealth Reform: Market-Based Medicaid in Tennessee," *Health Affairs* 15 (2) Summer 1996, 306-14; Jim Cooper (former congressman), "TennCare: Tennessee's Medicaid Experiment," Letter to the Editor in *Health Affairs* 15 (4), 282; and David M. Mirvis, et al., "TennCare--Health System

Reform for Tennessee," *Journal of the American Medical Association,"* (274) 15, October 18, 1995, 1235-1241.

7. In an extended discussion, *Medicine and Health* reports on four basic stages of health care market development as delineated by the American Practice Association. See Christina Kent, editor, "Perspectives," *Medicine and Health*, April 17, 1995, 1-4.

8. California, for instance, has undertaken some major Medicaid managed care efforts in the early 1970s. They turned out to be largely unsuccessful, but provided a body of lessons learned experience to draw upon in framing the more recent initiatives. See Sparer, *Medicaid and the Limits of State Health Reform.*

9. The California Medicaid program covers about 5.5 million enrollees. In contrast, the Rhode Island program covers a little more than 100,000. Clearly, the dimensions of the retooling challenges are very different in these two settings.

10. The complexity is greatly influenced by factors such as the number and type of carve-outs; the number and scope of relationships with other State agencies, with county governments, and with local service providers (such as community health centers); and the number of linguistic groups being served (about 40 in California)

11. In particular, these would involve State health departments and State departments responsible for licensure of insurance entities.

12. Given that our categories are general and that the pace of change in the States is often quite fast, any assignment of individual States to particular Stages, as we have done, can be risky. Perhaps the most difficult assignment in this regard is Massachusetts. At this writing, PCCM remains as the dominant mode of managed care in Massachusetts. However, the Medicaid agency has a substantial number of disabled enrolled in PCCM arrangements and the agency leadership has infused throughout much of the agency a purchaser orientation much like that we describe for Stage II or III States.

13. Our typology of five challenges omits one that might normally be regarded as one of the most prominent: the adequacy of staffing levels to carry out managed care responsibilities. In our presentation, that challenge is to some degree subsumed under some of the others, which we found more compelling. For instance, the challenges of establishing a core team and acquiring the necessary knowledge and skills clearly involve obtaining adequate numbers of staff.

None of this is meant to minimize the danger of managed care initiatives being jeopardized by having too few staff associated with their implementation. Indeed, in a recent review of five Section 1115 Medicaid managed care demonstration projects, the authors offer the following warning: "New programs need to have enough administrative resources." They add: "At least in the short term, states may require more administrative capacity, particularly if they are continuing to use fee-for-service for some populations or services." See Mathematica Policy research, Inc. and the Urban Institute, *Implementing State Health Care Reform: What Have We Learned From The First Year?*

The First Biannual Report of the Evaluation of Health Reform in Five States. Submitted to Office of research and Demonstrations, Health Care Financing Administration, December 18, 1996.

14. In Florida, responsibility for managed care is split between two offices. The full-risk component is led out of the Bureau of Managed Care in the Division of Quality Assurance. The PCCM initiative is run out of the fee-for-service operation in the Division of State Health Purchasing.

15. Of course, this complaint is not unique to managers in the Medicaid agency. Mangers in other State and Federal agencies regularly express similar concerns about the lack of flexibility afforded by personnel systems. But for an agency seeking to introduce a fundamental shift in its mission and operations, such inflexibility can present particularly serious problems.

16. Although perhaps a bit dramatically, one agency manager conveyed the seriousness of the situation as viewed by many Medicaid program staff: "Change is coming too fast to adjust employee perceptions. It's like stages of death. It's like a corporate merger. It's a rough transition. It's like mourning for a loss."

17. In Massachusetts, consultants from the University of Massachusetts interviewed staff and conducted focus groups involving staff. The effort identified some communication problems within the agency and led to a series of initiatives addressing them. These included an agencywide newsletter, regular off-site meetings with senior staff to discuss benefit plan progress, a survey of training needs, and some field reorganization.

18. In Missouri, after interviewing about 75 agency staff, a consultant developed a four-phase process to prepare the agency for the internal changes necessary to carry out expanded managed care responsibilities. It involved two retreats as well as consultant-facilitated task groups and technical assistance to help agency management and staff "make the necessary adjustments to the new structures and systems. . . "

19. As the State Medicaid agency that has gone the furthest in transforming itself from fee-for-service a managed care, the Oregon agency has a substantial body of experience to draw upon in further explaining the challenges of retooling and understanding the lessons learned in responding to them. Unfortunately, in our inquiry, our contacts with Oregon officials did not involve a site visit and were limited to brief telephone conversations; so in this report we are unable draw substantially on the Oregon experience. It does, we believe, warrant further examination, in the context of the issues raised in this report.

Of course, there is a substantial literature on Oregon's Medicaid reforms. See, for examples, Mathematica Policy Research (for the Kaiser Foundation and Commonwealth Fund), *Managed Care and Low-Income Populations: A Case Study of Managed Care in Oregon*, July 1995; and John A. Kitzhaber, "The Governor of Oregon on Medicaid Managed Care," *Health Affairs* (15) 3, Fall 1996, 167-69.

20. This was a particular problem for the Oregon agency when, in 1994, it was substantially expanding the number of individuals served by the Medicaid program. The fee-for-service provider relations staff found itself faced with significant increases in telephone inquiries and billing exceptions. Before long a substantial backlog developed which added to frustrations.

21. A politically sensitive point not usually emphasized by the architects of managed care reforms is that for a time dual managed care/fee-for-service systems will actually be more expensive to administer than traditional fee-for-service systems. It is not until sizeable decreases occur in fee-for-service claims volume that significant opportunities for administrative savings are likely to emerge.

22. In those agencies that are increasingly oriented toward a prudent purchasing perspective and explain their mission in those terms (as does the Ohio agency), the distinctions between fee-for-service and managed care may become increasingly blurred. According to former HCFA Administrator Bruce Vladeck and health care consultant Lynn Etheredge, this, in fact, is happening in health care markets across the country. See Robert Cunningham, editor, "Perspectives: Government as Purchaser: Making Policy by Contract," *Medicine and Health*, October 14, 1996, 1-4.

23. Consultants hired by State Medicaid agencies often recommend that TPL be delegated to health plans to simplify administration for the agency. As long as the capitated rate reflects prior levels of TPL recovery on the fee-for-service side, this delegation tends to be attractive to the Medicaid agencies.

24. A California Medicaid official has estimated that "without TPL savings, California's Medicaid costs would be over 20 percent higher." See Barbara V. Carr, "Who Manages Third Party Liability when a State Contracts its Medicaid Program to Managed Care Plans," March 1995.

25. See Jane Horvath, "Third Party Liability in Risk-Based Managed Care: Issues and Options," in National Academy for State Health Policy," *Medicaid Managed Care: A Guide for States*, 1995, III-65-81.

26. Office of Inspector General, Office of Evaluation and Inspections, "Surveillance and Utilization Review Subsystems' Case Referrals to Medicaid Fraud Control Units," (OEI-07-95-00030), November 1996.

27. The legislation exempted health plans contracting with Medicaid agencies from the requirements of the DUR program it set forth.

28. Office of Inspector General, Office of Evaluation and Inspections, "Medicaid Drug Use Review Programs: Lessons Learned by States," (OEI-01-92-00800), May 1995 (Draft Report).

29. "Experiences of Health Plans with Pharmacy Benefit Management Companies," (OEI-01-95-00110), December 1996.

30. In Massachusetts, for example, the Medicaid agency leadership treats its PCCM program as an internally managed health plan and manages its fee-for-service providers accordingly. This is reflected, for example, in its hospital contracting approaches and in its system of profiling "network managers" and providers.

31. California Department of Health Services, "Medical Case Management: A Successful Partnership," September 1995.

32. It also bears note that in May 1996, HCFA sent to the State Medicaid agencies a draft manual issuance that spells out various options available to the States in carrying out TPL responsibilities in managed care environments.

33. The Program Integrity Group has been established to address fraud and abuse issues affecting the Medicare and Medicaid programs.

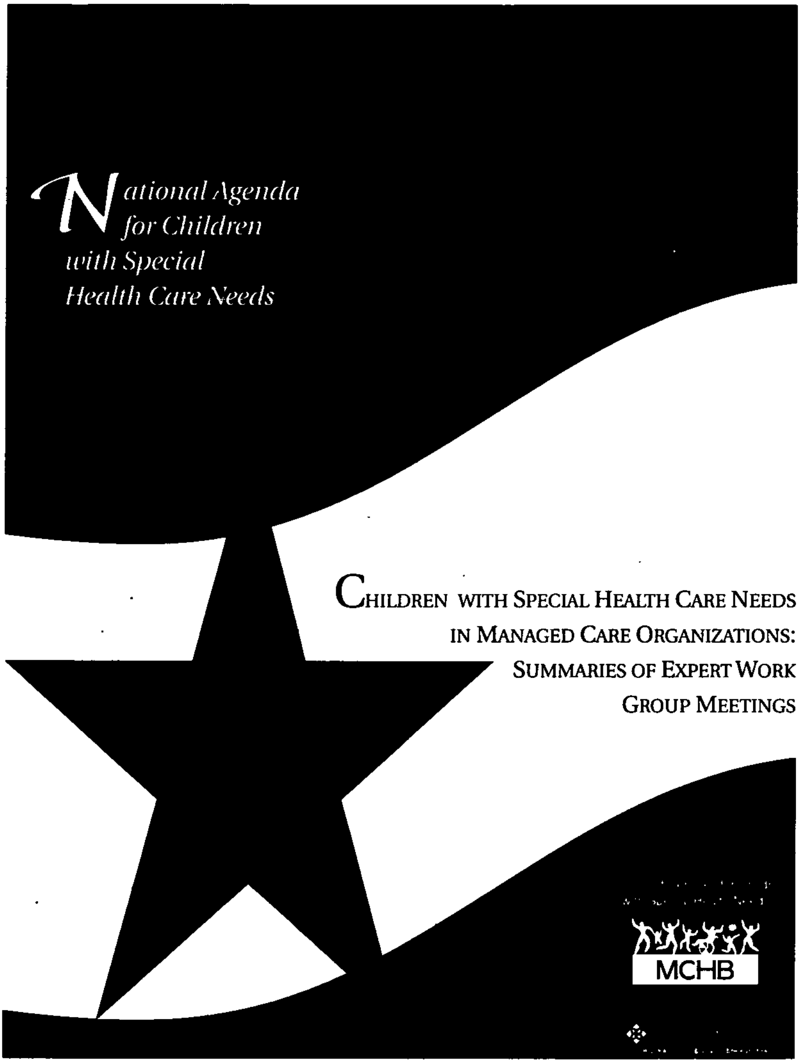
34. This and the following recommendation were made in our aforementioned report entitled, "Experiences of Health Maintenance Organizations with Pharmacy Benefit Management Companies."

35. The 1981 amendments also allow States to enroll Medicaid beneficiaries in limited-risk managed care organizations (i.e., no risk for inpatient care) that fail to meet Federal qualifications.

36. The following States have implemented their 1115 waivers: Alabama, Arizona, California, Delaware, Hawaii, Minnesota, Ohio, Oklahoma, Oregon, Rhode Island, Tennessee, and Vermont. The following States have approved 1115 waivers that are pending implementation: Florida, Illinois, Kentucky, Maryland, and Massachusetts. South Carolina has an approved waiver but no plans for implementation.

37. States with 1115 waivers under review are: Georgia, Kansas, Louisiana, Missouri, New Hampshire, New York, Texas, Utah, and Washington.

38. Federal regulations define comprehensive services as either inpatient hospital services and one other mandatory service or three or more mandatory services (42 CFR 434.21). Mandatory services are defined in statute as inpatient and outpatient care, physicians' services, and laboratory and diagnostic services, among others (42 USC §1396d(a)).



National Agenda
for Children
with Special
Health Care Needs

CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN MANAGED CARE ORGANIZATIONS: SUMMARIES OF EXPERT WORK GROUP MEETINGS

CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN MANAGED CARE ORGANIZATIONS:

DEFINITIONS AND IDENTIFICATION
FAMILY PARTICIPATION
CAPITATION AND RISK ADJUSTMENT
QUALITY OF CARE

Summaries of Expert Work Group Meetings

Division of Services for Children with Special Needs
Maternal and Child Health Bureau
Department of Health and Human Services
5600 Fishers Lane, Room 18A27
Rockville, MD 20857

December 1996

TABLE OF CONTENTS

Preface

The U.S. Maternal and Child Health Bureau (MCHB) has as its mission the establishment of family-centered, comprehensive, coordinated care for all children with special health care needs. These principles were first articulated by former Surgeon General C. Everett Koop in 1982 and again in the new MCHB National Agenda.[1] These principles have significantly changed the way services are provided to children and their families in this country.

While the principles set forth in the National Agenda have not changed, two major trends have taken place in the 1990s that will continue to influence how children receive health care services. First, the emergence of managed care has dramatically changed how health services are delivered and financed. Second, public health responsibilities are diminishing and shifting from the federal to state levels. As we make these transitions, it is critical that managed care programs, public and private purchasers, Title V agencies, families, and health professionals work together to reinforce and advance the gains made in the last two decades. Clearly, we still have a long way toward making the principles of family-centered, comprehensive, coordinated care a reality.

The MCHB recognizes that this is a critical time to provide national leadership to improve managed care services for children with special health care needs. We have developed a managed care strategic planning agenda that addresses seven areas:

1. defining and identifying children with special health care needs,
2. family participation,
3. capitation and risk adjustment,
4. quality of care,
5. pediatric provider and service requirements,
6. provider capacity development, and
7. health and related services integration.

---

[1] Maternal and Child Health Bureau: *National Agenda for Children with Special Health Care Needs: Achieving the Goals 2000*. Rockville, MD: MCHB, Health Resources and Services Administration, 1995.

During the past year, expert work groups for the first four priorities were convened, each for a day and a half meeting. Work group members included federal and state Title V officials, federal and state Medicaid agency staff, managed care plan representatives, pediatric providers, representatives from family organizations, and health services researchers.

This report is a summary of the proceedings from the first four meetings and for each it includes a problem statement, examples of current research and innovative approaches, and recommended activities. Also included is a listing of the expert work group members and bibliographic references. The report was prepared by the Maternal and Child Health Policy Research Center with the assistance of the Georgetown University Child Development Center. Copies of this report are also available through the MCH NetLink at the following address: http://www.ichp.ufl.edu/MCHB_MCH-NetLink.

The Maternal and Child Health Bureau will be considering these findings and recommendations along with others to develop new research and demonstration grant guidelines, technical assistance materials, and policy statements. In the coming year, MCHB plans to continue work on developing operational approaches for identifying children with special health care needs for managed care purposes. We will continue to keep you informed of this and other work on managed care.

Merle McPherson, M.D.
Director
Division of Services for Children with Special Health Care
Needs
Maternal and Child Health Bureau

I. DEFINING AND IDENTIFYING CHILDREN WITH SPECIAL HEALTH NEEDS

A. Problem Statement

No operational definition exists for identifying children with special health needs served in managed care organizations. As a result, these children often are not identified at all and, when they are, they usually include only those with the most severe and high-cost conditions. In the case of Medicaid, the identification of children with special health needs is usually limited to those who qualify for the Supplemental Security Income (SSI) program. While this approach offers some consistency across states, it is limited in that SSI only includes a small subset of children with chronic conditions. National estimates show that about three to four percent of all Medicaid-enrolled children are receiving SSI cash assistance. However, estimates from the National Health Interview Survey reveal that as many as ten percent of poor children have a disabling chronic condition and many more have chronic conditions that are not associated with disability or activity limitations. Overall, between 20 and 30 percent of all children have chronic conditions.

In the absence of any widely accepted approach for identifying special-needs children, plans, pediatric health professionals, Title V agencies, and others are hampered in their ability to:

- target certain families for managed care enrollment assistance,
- assign children to appropriate plans and primary care physicians,
- determine risk-adjusted capitation rates and other risk-sharing mechanisms that fairly compensate plans,
- design, implement, and monitor quality of care activities, including family satisfaction surveys appropriate to children with special health care needs, and
- conduct ongoing epidemiological and needs assessment studies.

B. Examples of Current Research and Innovative Approaches

Children with special health needs can be identified on the basis of diagnosis, function, service use or need, categorical eligibility, or some combination of these. Six different identification approaches are summarized below, three of which have not been released at the time of this publication's printing.

1. State Title V Program for Children with Special Health Care Needs' Eligibility Criteria (CSHCN)

Content	Children who are eligible for Title V typically have complex physical or developmental conditions, such as congenital anomalies, cystic fibrosis, cerebral palsy, epilepsy, hearing loss, and muscular dystrophies. Diagnostic lists are often used to identify eligible children.
Purpose	Eligibility criteria for Title V's CSHCN program
Approach	Diagnostic based
Testing and Use	Most state Title V CSHCN programs rely on diagnostic eligibility criteria.
Strengths	• This approach identifies most children with complex physical conditions at least in states with comprehensive listings. • Diagnostic information is readily available.
Limits	• Children with mental health conditions are seldom included. • Children at risk of chronic conditions are not included. • States vary in the listing of medical conditions covered.
Source	Institute for Child Health Policy: *The Directory of State Title V CSHCN Programs: Eligibility Criteria and Scope of Services*. Gainesville, FL: University of Florida, 1996.

2. Child Health Questionnaire (CHQ)

Content	Children with health and functional impairments are identified using parent and child questionnaires that address 14 concepts: physical functioning, bodily pain, role/social limitations-physical, general health perceptions, change in health, role/social limitations-emotional/behavioral, mental health, general behavior, self-esteem, emotional impact on the parent, impact on parent's personal time, limitations on family activities, and family cohesion.
Purpose	Health and functional status assessment
Approach	Function based
Testing and Use	National and international sites. Currently in use only for epidemiologic purposes.
Strengths	• The approach captures multi-dimensional aspects of health and function and can be used to assess the impact of children's illness on other family members. • The approach is well tested for children, though not specifically for children with special health care needs. • A set of assessment tools for school-aged children are complete and available, including scales of three different lengths. • Multiple translations are available.
Limits	• This is a generic assessment tool that was not designed with identification of children with special health care needs in mind. • There are no shorter versions for infants/pre-schoolers at this time (only a 100 item scale is available). • There are no specific questions on learning problems and disabilities. • Because of its subjective nature, the approach may be subject to gaming by health plans.
Source:	Landgraf JM, Abetz L, Ware JE: *Child Health Questionnaire: A User's Manual*. Boston: The Health Institute, New England Medical Center (forthcoming in December 1996).

3. Maternal and Child Health Bureau's Definition (MCHB)

Content	Children with special health care needs are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally.
Purpose	Planning and systems development for federal and state Title V Programs for Children with Special Health Care Needs

Approach	Service based
Testing and Use	1994 Disability Supplement to the National Health Interview Survey for epidemiologic estimates
Strengths	• This approach is inclusive of those with a chronic condition as well as those at risk. • Diagnosis or functional status information does not necessarily have to be collected. • Using a service-based approach allows for looking more broadly across conditions and functional levels.
Limits	• This approach would likely take into account in excess of 20 percent of all children. • The term "increased risk" is not defined. • Except for national testing, this definition has not yet been applied at a managed care plan level.
Source	McPherson M: *New Definition of Children with Special Health Care Needs.* Rockville, MD: Maternal and Child Health Bureau, 1995.

4. Supplemental Security Income Eligibility Criteria (SSI)

Content	Children who are SSI eligible must have a medically determinable physical or mental impairment that has lasted or is expected to last at least 12 months or result in death. The condition list of impairments includes over 100 conditions. Under The Personal Responsibility and Work Opportunities Reconciliation Act, children are no longer eligible solely on the basis of a functional impairment that is comparable to one that would prevent an adult from working or one that would substantially reduce a child's ability to function in age-appropriate manner.
Purpose	Eligibility determination for cash payments, Medicaid eligibility in most states, and referral to Title V's CSHCN program
Approach	Diagnostic and function based
Testing and Use	Used in state Disability Determination Service Agencies
Strengths	• This is the only operational model that integrates diagnostic and functional status information. • It is used by many state Medicaid agencies for setting risk-adjusted capitation rates.

Limits

- This approach identifies a very narrow population of children, primarily those with mental retardation and certain neurological and mental health diagnoses.
- Eligibility determination using the SSI approach is expensive.

Source National Commission on Childhood Disability: *Supplemental Security Income for Children with Disabilities*. Washington, DC: National Commission on Childhood Disability, 1995.

Questionnaire for Identifying Children with Chronic Conditions (QuICCC)

Content Children with chronic conditions lasting or expected to last 12 months are identified using a parent questionnaire that addresses: 1) functional limitations -- unable to play with other children, restricted in activities, difficulty feeding, dressing, washing, toileting, walking, and difficulty hearing, seeing or communicating; 2) reliance on compensatory modalities -- medication use, special diet, special equipment, and personal assistance; and 3) service use/need beyond routine care -- hospitalizations, doctor visits, nursing care or treatment, physical, occupational or speech therapy, psychological services, special arrangements at school, special instruction or other educational services, and need for unobtainable services.

Purpose Epidemiology

Approach Function and service-based

Testing and Use 1994 Disability Supplement to the National Health Interview Survey, national telephone survey, and New York inner-city sample. Currently in use only for epidemiologic purposes.

Strengths

- This assessment tool was designed specifically for children with special health care needs.
- It is focused on the child rather than the condition. Therefore, it can capture children who have functional problems but no diagnosis.
- It has been well tested for survey purposes and it will be available in the form of a survey instrument very soon.

Limits

- Since the tool was designed for survey purposes, it may not be applicable for assessing individual children with special health care needs in plans.
- The instrument was not designed to provide information on types, numbers, or severity of conditions, nor was it designed to identify children at risk of chronic conditions.
- The measure is subjective in that it relies on parent responses and could be subject to gaming by plans.

Source Stein REK, Westbrook LE, Bauman LJ: The questionnaire for identifying children with chronic conditions (QuICCC): A measure based on a noncategorical approach. *Pediatrics* (forthcoming).

6. National Association of Children's Hospitals and Related Institutions' Classification System (NACHRI)

Content Children with congenital and chronic physical, mental, emotional, behavioral, or developmental disorders that are expected to last 12 months or longer, or to have sequelae that last 12 months or longer, are identified on the basis of diagnoses. Some 3,700 ICD-9-CM diagnostic codes have been identified and assigned to body system and condition categories. Severity level and disease progression are also classified.

Purpose Estimating prevalence, profiling utilization and costs, and pricing and capitation risk adjustment

Approach Diagnostic and function-based

Testing and Use Medicaid and commercial health plan data from the state of Washington. Not yet available for managed care plans.

Strengths

- This approach requires only diagnostic information in the form of ICD-9-CM codes. Consequently, it may be relatively easy to implement in a variety of settings as long as diagnostic data are available.
- NACHRI is already well along in the development phase and the classification system is expected to be available in the next few months.

Limits

- This approach was designed to identify children with existing chronic conditions. It has limited ability to identify those at risk.
- Determining severity and disease progression, particularly among children with multiple conditions -- though criteria based and statistically tested -- may have certain limitations.

Source: National Association of Children's Hospitals and Related Institutions: *New NACHRI Classification System To Be Released for Children with Congenital and Chronic Health Conditions*. Alexandria, VA: National Association of Children's Hospitals and Related Institutions, 1996.

To evaluate these various identification approaches certain criteria might be applied. These include inclusivity, validity, reliability, cost, acceptability, availability, and flexibility.

1. *Inclusivity*

To what extent does the definition capture the population of children with special health care needs? Does it include children with or at risk of physical, behavioral, emotional, and developmental conditions that result in elevated service needs?

2. *Reliability*

   To what extent is the definition subject to measurement error? For example, a functional assessment of a chronic condition is subject to the biases of the person conducting the assessment. Even though children with special health care needs are acknowledged to share a range of issues across a broad spectrum of conditions, does the definition contain significant "gray areas" in its application, such as identifying children at risk of special needs? Would the definition be consistent across different health plans?

3. *Cost*

   What investment would be required to implement the definition? Do the benefits of identifying these children outweigh the primary data collection and administration costs associated with implementation?

4. *Acceptability*

   Is the definition and the steps required to implement it acceptable to payers, providers, and consumers? If not, is there a way to identify problem areas and to address them?

5. *Availability*

   To what extent is the definition operational or ready to be implemented for purposes of identifying children in managed care settings? Is additional developmental work needed? Has there been adequate testing of the definition to determine its validity and reliability?

6. *Flexibility*

   Is the definition consistent with the benefit package provided under Medicaid or commercial insurance plans? Are services available once a child with special health needs is identified? Evaluative criteria must be flexible to address new advances in condition recognition and intervention.

C. Recommended Activities

While there is no accepted operational approach that managed care plans can use to identify children with special needs, there are several alternate strategies states and plans might consider, each with its own strengths and weaknesses. These include diagnostic, functional, service, categorical, or combined approaches. The expert work group suggested several recommendations.

1. Most existing approaches for identifying children with special health needs have serious limitations. Several new tools will be available soon that will help improve the identification of these children, including those developed by Stein et al., NACHRI, and Landgraf. Until then, states should continue their efforts at developing creative identification mechanisms.

2. State Title V programs, plan managers, health professionals, families, and academics should begin to work together regarding the development and application of improved systems for identification, building on the new tools soon to be available.

3. Emerging efforts by states and managed care plans for identifying children with special health care needs should be monitored. Promising new efforts should be identified and evaluated.

4. Additional attention is needed to develop mechanisms for identifying children *at risk* for special service needs. Currently, there is little agreement in the field about which children are at risk.

5. A national profile of the number and characteristics of children with special health needs, based on MCHB's definition, should be developed using new information from the National Health Interview Survey on Disability. This profile can be used as a national baseline for monitoring changes over time in access, satisfaction, and use of services by children with special health needs.

II. FAMILY PARTICIPATION IN MANAGED CARE

A. Problem Statement

Over the past twenty years, policymakers, pediatric providers, and families have worked diligently to put the family at the center of care for children with special health care needs and to build family/professional partnerships. Families are concerned as they transition into new managed care arrangements that purchasers and plan administrators may not recognize the important role that they can play in care planning, quality assessment, and policy development. Without strong consumer input from families whose children have special health needs, managed care benefit packages, service authorization rules, quality performance measures, network development, and most importantly, provision of health care services, may wrongly assume that one-size fits all children.

While most managed care plans now seek some type of consumer feedback, generally the information gathered does not reflect the particular needs and concerns of children with special health care needs and their families, particularly those from diverse cultural and economic backgrounds. Also, information and education about selecting and using managed care services seldom address the unique issues and concerns of these families. Generic family information and education materials often say little about issues such as care coordination, access to specialty care, appeals processes, dispute resolution policies, family support services, and coordination with other community services. Finally, plan policies and procedures often ignore the specialized needs of this population of children and families. Using parents as liaisons with plan providers is not common and parent support activities are seldom included in plans. In addition, particular issues for children with special health care needs are not adequately represented in planning and decisionmaking. Just as public programs have become more responsive to families and more culturally competent due to consumer input, managed care organizations need the same input and education.

B. Examples of Current Research and Innovative Approaches

Greater family participation in managed care organizations can be accomplished by developing appropriate parent and child satisfaction survey questions, pertinent education and information materials, and collaborative family support initiatives. Several new efforts specifically designed for this population are described below.

FAMILY SATISFACTION SURVEYS

1. National Committee for Quality Assurance

Title	Medicaid HEDIS
Description	Potential topical modules for enrollee surveys include overall or summary measures; member characteristics; enrollment process and length of enrollment; health status and behavioral risk; use of health services; access to ambulatory care; access to particular types of care; wait times; office/clinic responsiveness to phone calls; access (language, race/ethnicity, cultural issues); barriers to access; convenience, safety, and comfort; understanding of managed care procedures; technical quality of care; quality of care - interpersonal and communication; quality of customer services; and special topics.
Source	National Committee for Quality Assurance: *Medicaid HEDIS.* Washington, DC: NCQA, 1996. (Request from NCQA, 2000 L Street, NW, Suite 500, Washington, DC 20036; Phone 202-955-3500.)

2. Agency for Health Care Policy and Research

Title	Consumer Assessments of Health Plans Study (CAHPS)

Description	This is an integrated set of carefully tested and standardized survey questionnaires for use by Medicaid, Medicare, and privately insured enrollees. It is being developed by a consortium at Harvard Medical School, Research Triangle Institute, and RAND. A core set of items will be used with all respondents, including enrollment/payment; demographics; perceived quality of health care -- access, preventive care, communication/interaction, continuity/coordination, access, administrative burden, and global evaluation; utilization; and perceived health status. Additional questions are being developed for use with certain subgroups, including persons with chronic or disabling conditions.
Source	Agency for Health Care Policy and Research: *Consumer Assessments of Health Plan Study (CAHPS)*. Rockville, MD: AHCPR, 1996; Phone 301-594-1349.

3. New England SERVE

Title	Ensuring Quality Project
Description	This project is developing a Family Survey on Managed Care that includes measures of family satisfaction as well as plan performance. The survey is designed to be used within a managed care plan as part of a quality improvement program. It is specifically targeted to families of children with special health needs. Measures are organized into the following eight domains: family participation and overall satisfaction with health plan; information available to families; written health care plan; primary care services; specialty care services; health services, supplies and equipment; mental health services; and care coordination.
Source	New England SERVE, 101 Tremont Street, Suite 812, Boston, MA 02108; Phone 617-574-9493.

4. New England SERVE and Family Voices

Title	Needs Assessment Family Survey on Managed Care

Description	This survey is designed to document family experiences in terms of access to and satisfaction with a broad range of health services paid for or provided through managed care. Topic areas include health insurance, family and child information, family satisfaction with medical and specialty services, communication and coordination, and ease of service delivery.
Source	New England SERVE, 101 Tremont Street, Suite 812, Boston, MA 02108; Phone 617-574-9493.

5. Michigan Department of Public Health, Children's Special Health Care Services

Title	Parent Survey
Description	This survey examines children's special health needs and enrollment in the Title V program, medical specialty care, primary care services, medical records, health insurance, family comments on satisfaction with access, and needed activities to better understand and cope with a chronic condition.
Source	Michigan Children's Special Health Care Services, 3423 N. Logan/Martin Luther King Jr. Boulevard, PO Box 30195, Lansing, MI 48909; Phone 517-335-8969.

FAMILY EDUCATION AND INFORMATION MATERIALS

1. National Coalition for Family Leadership

Title	The ABCs of Managed Care: Standards and Criteria for Children with Special Health Care Needs
Description	This report from a family summit includes principles of family-centered care, family-professional partnerships, access, flexibility, and community-based care. These principles were designed to guide the development of standards and criteria for plans in the areas of benefits, service capacity, decisionmaking, evaluation and data, and financing.
Source	National Coalition for Family Leadership: *The ABCs of Managed Care: Standards and Criteria for Children with Special Health Care Needs*. Trenton, MI: National Coalition for Family Leadership, 1996. To order, call 800-359-3722 or 505-867-2368.

2. American Academy of Pediatrics

Title	How to Use Your Managed Care Plan Effectively: Questions and Answers for Families with Children
Description	A series of 23 questions and answers ranging from choosing a primary care physician and specialist, decisions on medical necessity, services requiring prior approval and the process for obtaining it, and how to file a complaint.
Source	American Academy of Pediatrics: *How to Use Your Managed Care Plan Effectively: Questions and Answers for Families with Children.* Elk Grove Village, IL: AAP, 1995. To order, write Division of Publications, AAP, 141 Northwest Point Boulevard, PO Box 927, Elk Grove Village, IL 60009; Phone 800-433-9016.

COLLABORATIVE FAMILY SUPPORT INITIATIVES

1. Parents Helping Parents, Inc.

Title	Managed Care Health Plans -- Introducing Family-Centered Care
Description	In collaboration with Kaiser Permanente, a parent-directed Family Resource Center was established at a managed care site. This Center provides information and training to health professionals on family-centered care and cultural competence; it offers mentors for emotional support to parents and professionals and outreach to underserved communities; and it provides a computerized directory of health care resources and a parent liaison in the hospital.
Source	Parents Helping Parents, Inc. 3041 Olcott Street, Santa Clara, CA 95054; Phone 408-727-5775.

2. National MCH Resource Center

Title	Alternative Dispute Prevention and Resolution Systems and Processes for Children with Special Health Care Needs in Managed Care Settings

Description	This project is designed to enhance conflict management skills of families and health professionals to participate in negotiation and mediation in order to resolve disputes involving the provision and financing of health and related services. Teams of neutral third party mediators and fact finders in health care disputes have been created. Best practices in dispute prevention and resolution appropriate for children with special health care needs in managed care organizations have been identified and developed.
Source	National MCH Resource Center, Health and Disability, Boyd Law Building, University of Iowa, Iowa City, IA 52242; Phone 319-335-9067.

C. Recommended Activities

Given the limited activities currently underway by managed care plans to promote participation by parents whose children have special needs, the expert work group identified a series of additional activities aimed at assuring family-centered care. These included development of a national strategy for educating managed care plan administrators and providers, and new, more relevant questions for consumer satisfaction surveys. The specific recommendations are as follows.

1. A national strategy should be developed to educate managed care organizations about health issues specific to this population, the importance of and need for family-centered, culturally competent care in collaboration with MCHB, state Title V agencies, family organizations, researchers, foundations, advocacy groups, purchasers, and providers.

2. A training package to help educate plans should be prepared using existing materials developed with funding from MCHB and others. These materials could include information on children with special health needs, family-centered care and cultural competence, information strategies for family education, examples of best practices of how to obtain family input, and information about model programs for plan and family collaboration.

3. National organizations and research groups designing and conducting consumer satisfaction surveys should be encouraged to develop improved questions for families whose children have special needs. These would include the provider's

knowledge of a child's condition, the practice of family-centered care, provider's interpersonal skills, timeliness of prior authorization, plan policies that support families, continuity of care, care coordination, access to primary and specialized services, transportation and physical access to services, support for family involvement in clinical and policy decisionmaking, and the presence of a community system of services.

4. A marketing strategy is needed to promote the use of consumer surveys as good business; the importance of family-centered, culturally competent care for improved health outcomes and strong public relations with families and purchasers; and the expertise of Title V programs and families as resources.

5. Selected employers and state Medicaid agencies should be enlisted to help educate and encourage managed care organizations to regularly obtain consumer input about the care of children with special health care needs and to involve families in planning and decisionmaking.

III. CAPITATION AND RISK ADJUSTMENT

A. Problem Statement

Under capitation and prepayment, insurers in a competitive market will seek to enroll those with lower costs and avoid those with higher costs. Appropriate risk adjustment mechanisms are needed to avoid such practices. Children with special health needs (as compared to adults) pose unique challenges for setting capitation rates and adjusting for risk. Many of their conditions are of low prevalence and wide variation exists in severity and service needs. Certain conditions with higher prevalence -- behavioral, emotional, and developmental conditions -- often have been treated by a variety of publicly funded providers and undertreated by medical providers, making it difficult to obtain complete and reliable prior cost estimates for their treatment. Moreover, certain specialized health and related services are often "carved-out" of benefit packages, making computation of capitation rates and risk adjustment more difficult. Most importantly, unlike the adult field, there has been little research or modeling of appropriate risk adjustment mechanisms for children.

As more state Medicaid agencies move to enroll all children in fully capitated plans, carefully defining this population becomes more critical for reimbursement purposes. Many states identify only SSI-eligible children for risk adjustment and miss the substantial number of AFDC and foster care children with chronic conditions. Given the difficulties associated with obtaining reliable capitation and risk adjustment estimated for children with chronic conditions and the limited research on setting pediatric capitation rates and adjusting for risk, it is critical for state Medicaid agencies and other purchasers to examine a variety of risk-sharing methods and contractual requirements to avoid problems.

B. Examples of Current Research and Innovative Approaches

At least four classification systems have been developed for setting capitation rates, though only the NACHRI approach has been developed specifically for children with chronic conditions. Existing approaches are based on demographic models (age, sex, and geographic area), categorical eligibility models, prior expenditure models, diagnoses or diagnostic groupings, functional status or severity of illness measures, or service utilization groups. Four of the major diagnostic approaches are summarized below.

1. Ambulatory Care Groups (ACGs)

Purpose	Profiling and utilization review, quality assurance, capitation and risk adjustment
Predictors	Diagnosis, age, and sex
Method	6,000 diagnoses are assigned to 34 clusters or Ambulatory Diagnostic Groups (ADGs) on the basis of clinical judgement (service and functional needs) and statistical analysis. The 34 ADGs are collapsed into 12 "collapsed ADGs" or CADGs and they are assigned to 25 mutually exclusive major ambulatory group (MACs), then split into 51 mutually exclusive ACGs.
Testing and Use	Many HMOs, Maryland Medicaid, and international use
Strengths	• Takes into account ambulatory diagnoses and co-morbidities and now includes inpatient codes. • Validated on pediatric populations, though not specifically for children with special health needs. • Data system to implement ACGs is available.
Limits	• Individuals are classified into only one group, limiting the sensitivity of this approach. • Inability to adjust for severity of illness across patient groups. • No method exists for assigning payment to the diagnostic classification.

Sources	Smith NS, Weiner J: Applying population-based case mix adjustment in managed care: the Hopkins Ambulatory Care Group system. *Managed Care Quarterly*. 2:21-34, 1994. Weiner JP, Dobson A, Maxwell SL, Coleman K, Starfield BH, Anderson GF: Risk-adjusted Medicare capitation rates using ambulatory and inpatient diagnoses. *Health Care Financing Review*. 17:77-99, 1996. Weiner JP, Starfield BH, Lieberman RN: John Hopkins Ambulatory Care Groups (ACGs): a case-mix system for utilization review, quality assurance and capitation adjustment. *HMO Practice*. 6:13-19, 1991. Weiner J, Starfield B, Steinwachs D, Mumford L: Development and application of a population-oriented measure of ambulatory care case-mix. *Medical Care*. 29:452-461, 1991.

2. Diagnostic Cost Groups (DCGs)

Purpose	Alternative to the current Medicare payment method for risk-contracting HMOs
Predictors	Age, gender, welfare status, diagnosis, and prior utilization
Method	Classification system based on diagnosis and costs associated with hospitalizations lasting three days or longer. Nearly 800 diagnostic codes are aggregated into clinically meaningful subgroups and, using diagnostic and cost data from the Medicare population, collapsed into nine diagnostic cost groups.
Testing and Use	Medicare claims data
Strengths	• Individuals can be classified into more than one group. • Data to implement DCG system are available.
Limits	• Exclusively inpatient-based. • Developed for use in the Medicare population and has not been validated for pediatric populations.

Sources	Ash A, Porell F, Gruenberg L et al: Adjusting Medicare capitation payments using prior hospitalization data. *Health Care Financing Review.* 10:17-50, 1989. Ellis RP, Pope GC, Iezzoni LI, Ayanian JZ, Bates DW, Burstin H, Ash AS: Diagnosis-based risk adjustment for Medicare capitation payments. *Health Care Financing Review.* 17:101-128, 1996. Ellis RP, Ash A: *Refining the diagnostic cost group model: a proposed modification to the AAPCC for HMO reimbursement.* Report prepared under HCFA Cooperative Agreement No. 18-C-98526/1-03. Boston University, 1988.

3. Disability Payment System (DPS)

Purpose	Capitation and risk adjustment for disabled Medicaid recipients
Predictors	Diagnosis, age, and gender
Method	Classification system based on groups of diagnoses that are associated with elevated future costs. These are divided into 18 major categories that correspond to either body system or specific types of illness or disability. These 18 categories are divided into 43 subcategories according to degree of elevated future costs (high, medium, and low cost).
Testing and Use	Claims data for disabled Medicaid SSI recipients in Ohio and Missouri and then tested on Medicaid claims data from Colorado, Michigan, and New York. Colorado and Missouri are planning to use this method. Maryland, Massachusetts, Minnesota, and Washington are also considering it.
Strengths	• Individuals can be classified into more than one group. • Adjusts for degree of elevated costs. • Data to implement DPS are available.
Limits	• Developed originally for SSI adults, now being applied to SSI adults and children, and AFDC populations. • Less serious diagnoses associated with lower future costs were excluded from the system.

Sources	Kronick R, Dreyfus T, Lee L, Zhou Z: Diagnostic risk adjustment for Medicaid: the disability payment system. *Health Care Financing Review*. 17:7-33, 1996. Kronick R, Zhou Z, Dreyfus T: Making risk adjustment work for everyone. *Inquiry*. 32:41-55, 1995.

4. National Association of Children's Hospitals and Related Institutions' Classification System (NACHRI)

Purpose	Pricing and capitation risk adjustment, prevalence estimates, profiling utilization and costs
Predictors	Diagnosis and functional status
Method	Children with congenital and chronic physical, mental, emotional, behavioral, or developmental disorders -- expected to last 12 months or longer or have sequelae that last 12 months or longer -- are identified on the basis of diagnoses. Some 3,700 ICD-9-CM diagnostic codes have been identified and assigned to body system and condition categories. Severity level and disease progression are also classified.
Testing and Use	Medicaid and commercial health plan data from the state of Washington. Not yet available for managed care plans.
Strengths	• NACHRI is already well along in the development and testing phase and the classification system will be available in the next few months. • An extensive review of physical, mental, developmental, behavioral, and emotional conditions are classified. • This approach allows for classifying children with multiple chronic conditions.
Limits	• The data for this approach is not yet available nor widely tested. • States and plans are seeking a single classification software package for all nonelderly populations and may, therefore, not be as interested in a unique pediatric risk adjustment system.
Source	National Association of Children's Hospitals and Related Institutions: *New NACHRI Classification System To Be Released for Children with Congenital and Chronic Health Conditions*. Alexandria, VA: NACHRI, 1996.

C. Recommended Activities

With the exception of the NACHRI approach, none of the existing risk adjustment approaches were developed specifically for children with special health needs. Consequently, managed care plans and pediatric providers face significant uncertainty and financial disincentives in caring for children with special health needs. The expert work group identified several recommendations for the development of improved pediatric risk adjustment models, risk-sharing mechanisms, and regulatory oversight.

1. More research is urgently needed to develop risk adjustment models appropriate for children with special health needs. An inclusive group of Medicaid officials, actuaries, researchers, plans, providers, public program directors, and families should participate in the design, review, and selection of new pediatric capitation and risk-sharing arrangements.
2. A new comparative analysis of the strengths and limits of the existing capitation risk adjustment approaches for children with chronic conditions should be performed using several Medicaid and commercial data sets.
3. A combination of risk adjustment, reinsurance, and carve-out strategies is needed to prevent serious financial difficulties while rewarding high quality care among plans and providers serving high-cost children.
4. Regulatory strategies, contract requirements, and oversight must accompany risk adjustment strategies, given the nature of the competitive market and the less than perfect science of pediatric risk adjustment.
5. Previous patterns of underutilization, particularly among children with developmental, behavioral, and emotional problems, must be taken into consideration when developing appropriate capitation rates.

IV. QUALITY OF CARE

A. Problem Statement

The state-of-the-art in assessing quality of care both at the managed care plan level and state and community system level for children with or at risk of chronic conditions is very limited. At the plan level, performance measures specifically targeted for this population have been difficult to develop for several reasons. The time and cost associated with developing practice guidelines is enormous. Relatively few pediatric practice guidelines exist, restricting plans' ability to adequately judge outcomes of care. Also, given the nature of childhood chronic conditions -- few prevalent and many rare conditions with large differences in functional impacts and frequent co-morbidities -- it is unlikely that major quality gains will come by proceeding condition by condition, except for the most prevalent conditions. Further complicating progress in developing quality measures at the plan level is the absence of a uniform definition, the concern of many managed care plans regarding adverse selection if they do a good job in this area, and the competing demands on plans to collect an unprecedented amount of quality data to meet new accreditation standards and contractual requirements.

At the systems level, performance measures have lagged behind the development of individual or plan measures. A core set of well-tested indicators, comparable to HEDIS, do not exist for monitoring the quality of state and community-based systems for children with special health needs. The organization, financing, and delivery health services for this population varies tremendously across and within states and communities making comparability almost impossible. Also, unlike encounter data and medical records, data sources for monitoring state and community systems performance are very limited. Finally, still unresolved is the question of authority and responsibility for conducting system-wide performance reviews for children. Is this the function of the Title V program, the Medicaid agency, or the state health department?

B. Examples of Current Research and Innovative Approaches

Quality indicators are needed for a number of purposes -- accreditation by outside organizations, external monitoring for the purpose of population-based planning and regulation, marketing to provide information to purchasers and consumers, and internal management of the plan. There are numerous efforts underway to measure these different aspects of quality. Some are focused on developing improved measures for structure, process, or outcome and others are aimed at developing conceptual frameworks. Several of these new initiatives are summarized below.

1. Medicaid Health Plan Employer Data and Information Set (HEDIS)

Purpose	Provide state Medicaid agencies with information on the performance of their managed care contractors, assist managed care plans in their quality improvement efforts, support emerging efforts to inform Medicaid beneficiaries about plan performance, and promote standardization of managed care plan reporting across the public and private sectors.
Relevant Quality Indicators	• Utilization measures -- ambulatory care, newborn care, mental health, and chemical dependency • Access measures -- availability of mental health providers and low birthweight deliveries at facilities for high-risk deliveries and neonates • Quality measures -- substance abuse counseling for adolescents; low birthweight rate; ambulatory follow-up after admission for specified mental disorders; and asthma inpatient admission rate • General plan managements measures -- quality and service improvement studies; case management; utilization management; arrangements with public health, education, and social service entities; new member orientation and education; and pediatric mental health services
Source	National Committee for Quality Assurance: *HEDIS 3.0 Draft: Health Plan Employer Data and Information Set*. Washington, DC: NCQA, 1996. (Request from NCQA, 2000 L Street, NW, Suite 500, Washington, DC 20036; Phone 202-955-3500.)

2. Agency for Health Care Policy and Research's COmputerized Needs-oriented QUality measurement Evaluation SysTem (CONQUEST 1.0)

Purpose	Provide a classification scheme and database that identifies and summarizes available information on clinical performance measures. The measure database includes 1,185 measures and the condition database contains 52 conditions.
Relevant Quality Indicators	The condition database includes the following pediatric chronic care measures: ADHD; anorexia nervosa; anxiety; asthma; bulimia nervosa; early HIV infection; diabetes - Type I, II; otitis media-acute, with effusion; pediatric HIV positive; schizophrenia; and sickle cell disease.
Source	Center for Quality of Care Research and Evaluation: *Conquest 1.0: A COmputerized Needs-oriented QUality measurement Evaluation SysTem*. Boston, MA: Harvard School of Public Health, 1996. (Request from Center for Quality of Care Research and Education, Harvard School of Public Health, Boston, MA 02115; Phone 617-432-3270.)

3. American Academy of Pediatrics' Quality Initiatives

Purpose	Conduct, coordinate, and disseminate research on improved pediatric care.
Relevant Quality Projects	• The Functional Outcomes Project is developing condition-specific measures for asthma, otitis media, juvenile rheumatoid arthritis, and head injury. The functional areas that are assessed include physical activity, emotional health, social interactions, and health care utilization. These are currently in a pilot-test phase. The long-range goal of this project is to develop measures for several of the most common or serious conditions affecting children.

- The Practice Parameters Project is designed to provide pediatricians with state-of-the-art practice guidelines, including patient management and clinical decisionmaking tools. To date, practice parameters for acute asthma, hyperbilirubinemia, otitis media, evaluation of febrile seizures, and acute gastroenteritis have been published. New practice parameters are being developed for minor and serious head trauma, diagnosis and treatment of urinary tract infection, developmental hip dysplasia, fever, wheezing in young children, diabetes mellitus, treatment of febrile seizures, and attention deficit/hyperactivity disorder.
- The Ambulatory Care Quality Improvement Program assists pediatricians in evaluating their practices and comparing them to their peers in the areas of practice management, clinical management, and patient satisfaction.

Source Department of Research, Division of Quality Care, American Academy of Pediatrics, 141 Northwest Point Boulevard, PO Box 927, Elk Grove Village, IL 60009; Phone 800-433-9016.

4. National Association of Children's Hospitals and Related Institutions' Pediatric Excellence in Health Delivery Systems

Purpose Provide a framework, criteria, and measures for an integrated pediatric health system that meets the needs of all children.

Relevant Quality Indicators

- Primary care, acute, and chronic care -- screening, child/family education, prevention, access, comprehensiveness, coordination and continuity, accountability and responsibility.
- System-wide -- education and training, quality assurance, community interface, and health information linkage.

Source National Association of Children's Hospitals and Related Institutions. *Pediatric Excellence in Health Delivery Systems*. Alexandria, VA: NACHRI, 1996. (Request from NACHRI, 401 Wythe Street, Alexandria, VA 22314; Phone 703-684-1355.)

5. Other Relevant Quality Initiatives

RAND

Title	Development of Global Quality Assessment Tool for Women and Children
Description	This project is developing a comprehensive set of primarily process measures for children. Plans will be scored on their performance across several dimensions of care -- screening, diagnosis, treatment, and follow-up. The children's health care measure set contains 515 pediatric and adolescent indicators addressing 23 conditions, including acne, allergic rhinitis, asthma, attention deficit/hyperactivity disorder, cesarean delivery, depression, developmental screening, diabetes, diarrhea, family planning, fever, headache, immunization, medication prescription errors, otitis media, prenatal care, adolescent preventive care, sickle cell anemia, tuberculosis, upper respiratory infections, urinary infections, vaginitis/STDs, and well child care.
Source	RAND, 1700 Main Street, Santa Monica, California, 90401.

New England SERVE

A. Title Ensuring Quality Project

Description A model for monitoring the quality of family-centered care provided for children with special health care needs in managed care settings is being developed. Data collection instruments will include measures of family and provider satisfaction, plan performance, as well as administrative information, as follows:

- Family Survey: Family participation and overall satisfaction with health plan information available to families, written health care plan, primary care services, specialty care services, health services supplies and equipment, mental health services, and care coordination.
- Provider Survey: Policies and supports to deliver quality primary care, special care, related health services, supplies and equipment, mental health, and care coordination.

- Administrative Survey: Enrollment of children with special health care needs, service delivery network, case management/care coordination services, grievance/appeals mechanisms, ease of service delivery, consumer participation in governance.

A definition of children with special health care needs that includes functional and service utilization components and allows managed care plans to identify the target population will also be included.

Source New England SERVE, 101 Tremont Street, Suite 812, Boston, MA 02108; Phone 617-574-9493.

B. Title Enhancing Quality: Standards of Quality Care for Children with Special Health Care Needs.

Description This manual includes standards and indicators that define specific characteristics and components of quality care for children with special health care needs. It is organized into five sections: individualized services, health care professional and team characteristics, health care agency or facility responsibilities, state health department responsibilities, and guidelines for community and societal support.

Source New England SERVE: *Enhancing Quality: Standards of Quality Care for Children with Special Health Care Needs*. Boston, MA: New England SERVE, 1989. New England SERVE, 101 Tremont Street, Suite 812, Boston, MA 02108; Phone 617-574-9493.

Maternal and Child Health Bureau

Title A Preliminary Strategy for Assessing Community Systems of Care for Women, Children, and Adolescents

Description This set of community systems measures is designed to track progress in creating improved service systems for all women and children, including those with special health needs. It is based on the principles of Communities Can and is organized into five areas: 1) early identification and referral system; 2) primary and specialized health service network; 3) family satisfaction and quality of care; 4) assessment, development, and coordination of primary, specialized, and related services; and 5) family participation.

Source

Maternal and Child Health Bureau: *A Preliminary Strategy for Assessing Community Systems of Care for Women, Children and Adolescents*. Rockville, MD: MCHB, 1995. (Request from Division of Services for Children with Special Health Care Needs, Maternal and Child Health Bureau, Parklawn Building, Room 18A27, 5600 Fishers Lane, Rockville, MD, 20857; Phone 301-443-2350.)

Johns Hopkins Child and Adolescent Health Policy Center

Title

MCH Quality Functions Framework

Description

This framework is divided into the three public health functions and provides a list of individual, plan, and community/state measures. Function 1 is an assessment of health system populations, environment, structure, process, and outcomes that can be measured in terms of health risks, health status, health service capacity and adequacies, and health services utilization. Function 2 is assurance of risk-appropriate health services that includes standard setting and ensuring compliance, prevention programming, and enabling access for underserved populations. Function 3 is coordination of service delivery and systems within communities, using health care continuum and community services integration measures.

Source

The Child and Adolescent Health Policy Center: *MCH Policy Brief: Quality, Quality Assessment, and Quality Assurance Considerations for Maternal and Child Health Populations and Practitioners*. Baltimore, MD: The Johns Hopkins University, 1995. (Request from The Child and Adolescent Health Policy Center, The Johns Hopkins University, 624 North Broadway, Baltimore, MD 21205; Phone 410-550-5443.)

The University of Illinois at Chicago, Division of Special Care of Children

Title

Quality Community Managed Care: A Guide for Quality Assurance Measures for Children with Special Health Care Needs.

Description	This guide provides a set of measures that can be used to monitor children with special health care needs in managed care plans. Selected Medicaid HEDIS measures related to children are abstracted along with a set of measures developed by the Quality Community Managed Care Project. The measures are organized into the following HEDIS categories: membership, utilization, quality, access, health plan management, clinical management systems, and finance.
Source	Monahan C, Harder-Shanahan R, Maloney M, Song J: *Quality Community Managed Care: A Guide for Quality Assurance Measures for Children with Special Health Care Needs*. Chicago, IL: The University of Illinois at Chicago, 1996 (draft). The University of Illinois at Chicago - Division of Specialized Care for Children, 1919 W. Taylor Street, 8th Floor, Chicago, IL 60612; Phone 312-996-1360.

Minnesota Department of Health and Health Partners

Title	Project ACCORD
Description	The project was designed to create a public-private partnership between the state health department, HMOs, and key organizations within the state to facilitate statewide adoption of practice guidelines. The special health condition used is pediatric asthma. Success is measured in terms of the rate of children with severe asthma who are on anti-inflammatory medication and the rate of parents who report a written asthma plan. Implementation goals are to identify and correctly diagnose asthma in children, provide optimal asthma management through education and avoidance of triggers, and establish a comprehensive pharmacological treatment and asthma action plan.
Source	Project ACCORD, Minnesota Department of Health 717 Delaware Street, Minneapolis, MN 55440; Phone 612-623-5140.

C. Recommended Activities

The major tools used to evaluate quality of care, including NCQA's HEDIS, have limited applicability for children with special health care needs. Short and long term recommendations for quality improvement initiatives follow.

1. A series of core, integrated quality of care measures related to the care of children with special health care needs should be developed and submitted to NCQA's Committee on Performance Measurement and to HCFA for the upcoming revision of the Quality Assurance Reform Initiative.

2. Emerging initiatives for assuring quality of care to children with special health needs should be evaluated and disseminated as appropriate to states. State Title V programs must work with their state Medicaid agencies to encourage them to adopt specific contract requirements for quality performance for this population.

3. Multidisciplinary consortia, including pediatric providers and families, should be formed to design and implement short-term quality improvement studies.

4. Pediatric practice guidelines should be centrally collected, organized, reviewed, and disseminated. Making these guidelines available to families, through focused educational efforts, would represent an important quality of care activity.

5. The example of asthma represents an important measure from which to expand to other chronic childhood conditions.

6. The role of Title V in monitoring, evaluating, and ensuring compliance in quality of care in managed care should be expanded. This will require strengthening the skills and capacity of states in this area and gaining authority to assume a greater role in quality of care.

APPENDIX I: PARTICIPANT LIST

MANAGED CARE EXPERT WORK GROUP ON DEFINING AND IDENTIFYING CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Mike Adams
Centers for Disease Control and Prevention
Atlanta, GA

Polly Arango
Family Voices
Algodones, NM

Marilyn Falik
MDS Associates
Wheaton, MD

Theresa Fama
Group Health Foundation
Washington, DC

Harriette Fox
Maternal and Child Health
Policy Research Center
Washington, DC

James Gay
Vanderbilt University Medical Center
Nashville, TN

Joe Hollowell
Centers for Disease Control and Prevention
Atlanta, GA

Cassie Lauver
Kansas Department of Health and Environment
Topeka, KS

Jeanne Landgraf
New England Medical Center
Boston, MA

Peggy McManus
Maternal and Child Health
Policy Research Center
Chevy Chase, MD

Merle McPherson
Maternal and Child Health Bureau
Rockville, MD

John Muldoon
National Association for Children's Hospitals and
Related Institutions
Alexandria, VA

John Neff
Children's Hospital and Medical Center
Seattle, WA

Richard Nelson
The University of Iowa
Iowa City, IA

Paul Newacheck
Maternal and Child Health
Policy Research Center
San Francisco, CA

Vincent Pearson
Independence Blue Cross Association
Philadelphia, PA

James Perrin
Massachusetts General Hospital
Boston, MA

Beth Roy
Maternal and Child Health Bureau
Rockville, MD

Jack Shonkoff
Brandeis University
Waltham, MA

Ruth Stein
Jacobi Medical Center
Bronx, NY

Bonnie Strickland
Maternal and Child Health Bureau
Rockville, MD

MANAGED CARE EXPERT WORK GROUP ON FAMILY PARTICIPATION

Polly Arango
Family Voices
Algodones, NM

Julianne Beckett
Family Voices
Cedar Rapids, IA

Suzanne Bronheim
Georgetown University Child Development Center
Washington, DC

Susan Burke
Arizona Department of Health Services
Phoenix, AZ

Diana Denboba
Maternal and Child Health Bureau
Rockville, MD

Deborah Drayer
Health Care Financing Administration
Baltimore, MD

Floyd Fowler
University of Massachusetts
Boston, MA

Josephine Gittler
National Maternal and Child Health Resource Center
Iowa City, IA

Kay Guirl
Maternal and Child Health Bureau
Rockville, MD

Jan Hanson
Institute of Family-Centered Care
Bethesda, MD

Henry Ireys
Johns Hopkins University
Baltimore, MD

Phyllis Magrab
Georgetown University Child Development Center
Washington, DC

John Mann
Kaiser Permanente
San Jose, CA

Peggy McManus
Maternal and Child Health Policy Research Center
Chevy Chase, MD

Merle McPherson
Maternal and Child Health Bureau
Rockville, MD

Andrew Nelson
Health Partners
Bloomington, MN

Florene Stewart Poyadue
Parents Helping Parents, Inc.
Santa Clara, CA

John Reiss
Institute for Child Health Policy
Gainesville, FL

Beth Roy
Maternal and Child Health Bureau
Rockville, MD

Joshua Seidman
National Committee for Quality Assurance
Washington, DC

Bonnie Strickland
Maternal and Child Health Bureau
Rockville, MD

Tawara Taylor
Georgetown University Child Development Center
Washington, DC

Kaye Vander Ven
Maternal and Child Health Bureau
Rockville, MD

Nora Wells
Federation for Children with Special Needs
Boston, MA

MANAGED CARE EXPERT WORK GROUP ON CAPITATION AND RISK ADJUSTMENT

Gerard Anderson
Johns Hopkins University
Baltimore, MD

Don Blanchon
Health Services for Children with Special Needs, Inc.
Washington, DC

Paul Boben
Health Care Financing Administration
Baltimore, MD

Suzanne Bronheim
Georgetown University Child Development Center
Washington, DC

Anne Darnay
HealthPartners
Minneapolis, MN

Stephanie Davis
Arizona Health Care Cost Containment System
Phoenix, AZ

Marilyn Falik
MDS Associates
Wheaton, MD

Teresa Fama
Group Health Foundation
Washington, DC

Lindsey Grossman
Children's Hospital
Columbus, OH

Richard Kronick
University of California School of Medicine, San Diego
La Jolla, CA

John MacQueen
National Maternal and Child Health Resource Center
Iowa City, IA

Ruth Martin
Center for Health Care Strategies
Princeton, NJ

Peggy McManus
Maternal and Child Health Policy Research Center
Chevy Chase, MD

Merle McPherson
Maternal and Child Health Bureau
Rockville, MD

John Muldoon
National Association of Children's Hospital and Related Institutions
Alexandria, VA

Paul Newacheck
Maternal and Child Health Policy Research Center
San Francisco, CA

Peter Rappo
Pediatric Associates
North Easton, MA

Beth Roy
Maternal and Child Health Bureau
Rockville, MD

Betsy Shenkman
Institute for Child Health Policy
Gainesville, FL

Gordon Trapnell
Actuarial Research Corporation
Annandale, VA

Ronald Uken
Michigan Department of Community Health
Lansing, MI

Joan Wasserman
University of Texas Medical School at Houston
Houston, TX

Jay Wolfson
University of South Florida
Tampa, FL

MANAGED CARE EXPERT WORK GROUP ON QUALITY OF CARE

Betsy Anderson
Federation for Children with Special Needs
Boston, MA

David Bergman
Lucile Salter Packard Children's Hospital
Palo Alto, CA

Suzanne Bronheim
Georgetown University Child Development Center
Washington, DC

Bev Crider
Michigan Department of Community Health
Detroit, MI

Christine Crofton
Agency for Health Care Policy and Research
Rockville, MD

Diana Denboba
Maternal and Child Health Bureau
Rockville, MD

Marilyn Falik
MDS Associates
Wheaton, MD

Sharon Kaufer Flores
HealthPartners
Minneapolis, MN

Harriette Fox
Maternal and Child Health Policy Research Center
Washington, DC

Shirley Girouard
National Association of Children's Hospitals and
Related Institutions
Alexandria, VA

Maridee Gregory
California Department of Health Services
Sacramento, CA

Neal Halfon
University of California at Los Angeles
Los Angeles, CA

David Hirsch
Phoenix Pediatrics
Phoenix, AZ

Jeanne Ireland
Maternal and Child Health Bureau
Rockville, MD

Henry Ireys
Johns Hopkins University
Baltimore, MD

John MacQueen
National Maternal and Child Health Resource Center
Iowa City, IA

Peggy McManus
Maternal and Child Health Policy Research Center
Chevy Chase, MD

Merle McPherson
Maternal and Child Health Bureau
Rockville, MD

Lynda Miller
Miller Healthcare Consulting
Mesa, AZ

Peter Miller
Family Health Outcomes Project
San Anselmo, CA

Colleen Monahan
University of Illinois at Chicago
Chicago, IL

Ann O'Fallon
Minnesota Department of Health
Minneapolis, MN

Lynn Olson
American Academy of Pediatrics
Elk Grove Village, IL

Ann Page
Institute for Health Policy Solutions
Washington, DC

Julie Radoslovich
Health Care Financing Administration
Baltimore, MD

Clifford Sells
Child Development and Rehabilitation Center
Portland, OR

Kaye Vander Ven
Maternal and Child Health Bureau
Rockville, MD

Deborah Klein Walker
Massachusetts Department of Public Health
New England SERVE
Boston, MA

APPENDIX II: BIBLIOGRAPHY

MANAGED CARE EXPERT WORK GROUP ON DEFINING AND IDENTIFYING CHILDREN WITH SPECIAL HEALTH CARE NEEDS

1) American Academy of Pediatrics, Committee on Children With Disabilities: Why supplemental security income is important for children and adolescents. *Pediatrics*, 95: 603-608, 1995.

2) Institute for Child Health Policy: *The Directory of State Title V CSHCN Programs: Eligibility Criteria and Scope of Services*. Gainesville, FL: University of Florida, 1996. (Request from the Institute for Child Health Policy, 5700 S.W. 34th Street, Suite 323, Gainesville, FL 32608; Phone 352-392-5904.)

3) Landgraf JM, Abetz L, Ware JE: *Child Health Questionnaire (CHQ): A User's Manual*, in press. (Request from Child Health Assessment Project, The Health Institute, NEMCH-Box 345, 750 Washington Street, Boston, MA 02111; Phone 617-636-8098.)

4) Maternal and Child Health Bureau: *National Agenda for Children with Special Health Care Needs: Achieving the Goals 2000*. Rockville, MD: Maternal and Child Health Bureau, 1995. (Request from Division of Services for Children with Special Health Care Needs, Maternal and Child Health Bureau, Parklawn Building, Room 18A27, 5600 Fishers Lane, Rockville, MD, 20857; Phone 301-443-2350.)

5) McManus M, Fox H, Newacheck P, McPherson M, and Roy B: *Strengthening Partnerships Between State Programs for Children with Special Health Needs and Managed Care Organizations*. Chevy Chase, MD: McManus Health Policy, Inc., August 1995. (Request from McManus Health Policy, Inc., 2 Wisconsin Circle, Suite 700, Chevy Chase, MD 20815. Phone: 202-686-4797. Also available via the internet at http://www.ichp.ufl.edu/MCHB_MCH-NetLink/MCHPRC/.)

6) McPherson M: *New Definition of Children with Special Health Care Needs*. Rockville, MD: Division of Services for Children with Special Health Care Needs, MCHB, HRSA, August 1995. (Request from Division of Services for Children with special health care needs, Maternal and Child Health Bureau, Parklawn Building, Room 18A27, 5600 Fishers Lane, Rockville, MD, 20857. Phone: 301-443-2350.)

7) National Association of Children's Hospital and Related Institutions: *NACHRI Classification System for Children with Congenital and Chronic Health Conditions*. Alexandria, VA: NACHRI, 1996. (Request from NACHRI, 401 Wythe Street, Alexandria, VA 22314. Phone 703-684-1355.)

8) National Commission on Childhood Disability: *Supplemental Security Income for Children with Disabilities*. Washington, DC: National Commission on Childhood Disability, 1995. (Request from the National Commission on Childhood Disability, 801 Pennsylvania Avenue, NW, Suite 625, Washington, DC 20004; Phone 202-272-2228.)

9) Stein REK, Westbrook LE, Bauman LJ: The questionnaire for identifying children with chronic conditions (QuICCC): a measure based on a noncategorical approach, *Pediatrics*, in press.

10) Stein REK, Bauman LJ, Westbrook LE, Coupley SM, Ireys HT: Framework for identifying children who have chronic conditions: the case for a new definition, *Journal of Pediatrics*, 122:342-327, 1993.

11) Tobias C, Master R, Kronick R: *Defining the Target Population: Policy and Program Development Issues*. Boston, MA: Medicaid Working Group, 1995. (Request from Medicaid Working Group, 441 Stuart Street, 6th Floor, Boston, MA 02116; Phone 617-437-1550.)

MANAGED CARE EXPERT WORK GROUP ON FAMILY PARTICIPATION

1) American Academy of Pediatrics: *How to Use Your Managed Care Plan Effectively: Questions and Answers for Families with Children*. Elk Grove Village, IL: AAP, 1995. (Request from Division of Publications, American AAP, 141 Northwest Point Boulevard, PO Box 927, Elk Grove Village, IL 60009; Phone 800-433-9016).

2) Agency for Health Care Policy and Research: *Consumer Assessments of Health Plan Study (CAHPS)*. Rockville, MD: AHCPR, 1996. (Request from 301-594-1349.)

3) Family Voices: *Family Voices Perspectives on Managed Care: Pilot Survey Report*. Algodones, NM: Family Voices, 1996. (Request from Family Voices, PO Box 769, Algodones, NM 87001; Phone 505-867-2368.)

4) Gold M, Woodridge J: Surveying consumer satisfaction to assess managed care quality. *Health Care Financing Review*. 16:155-173, 1995.

5) Michigan Children's Special Health Care Services: *Parent Survey*. Lansing, MI: Michigan Department of Public Health, 1996. (Request from Children's Special Health Care Services, 3423 N. Martin Luther King Boulevard, PO Box 30195, Lansing, MI 48909; Phone 517-335-8969.)

6) National Coalition for Family Leadership: *ABC's of Managed Care Standards and Criteria for CSHCN: A Report from the Egg Harbor Family Summit*. National Coalition for Family Leadership: Trenton, MI, 1996. (Request from National Coalition for Family Leadership, 800-359-3722 or 505-867-2368).

7) National Committee for Quality Assurance: *Medicaid HEDIS (An Adaptation of NCQA's Health Plan Employer Data and Information Set 2.0/2.5)*. Washington, DC: NCQA, 1995 (Request from NCQA, 2000 L Street, NW, Suite 500, Washington, DC 20036; Phone 202-955-3500.)

8) New England SERVE and Family Voices: *Family Survey on Managed Care*. Boston, MA: New England SERVE. (Request from New England SERVE, 101 Tremont Street, Boston, MA 02108; Phone 617-574-9493.)

MANAGED CARE EXPERT WORK GROUP ON CAPITATION AND RISK ADJUSTMENT

1) Ellis RP, Pope GC, Iezzoni LI, Ayanian JZ, Bates DW, Burstin H, Ash AS: Diagnosis-based risk adjustment for Medicare capitation payments. *Health Care Financing Review*. 17:101-128, 1996.

2) Fowler EJ, Anderson GF: Capitation adjustment for pediatric populations. *Pediatrics*. 98:10-17, 1996.

3) Kronick R, Dreyfus T, Lee L, Zhou Z: Diagnostic risk adjustment for Medicaid: the Disability Payment System. *Health Care Financing Review*. 17:7-33, 1996.

4) Kronick R, Zhou Z, Dreyfus T: Making risk adjustment work for everyone. *Inquiry*. 32:41-55, 1995.

5) Medicaid Working Group: *Risk-Adjusted Reimbursement for People with Disabilities: A Diagnostic Approach Proposed for Missouri*. Boston, MA: Medicaid Working Group, 1995. (Request from Medicaid Working Group, 441 Stuart Street, 6th Floor, Boston, MA 02116; Phone 617-437-1550.)

6) National Association of Children's Hospitals and Related Institutions: *New NACHRI Classification System To Be Released for Children with Congenital and Chronic Health Conditions*. Alexandria, VA: National Association of Children's Hospitals and Related Institutions, 1996. (Request from NACHRI, 401 Wythe Street, Alexandria, VA 22314. Phone 703-684-1355.)

7) Neff JM, Anderson GF: Caring for the uninsured and underinsured: Protecting children with chronic illness in a competitive marketplace. *Journal of the American Medical Association*. 274:1866-1869, 1995.

8) Smith NS, Weiner J: Applying population-based case mix adjustment in managed care: The Hopkins Ambulatory Care Group system. *Managed Care Quarterly*. 2:21-34, 1994.

9) Weiner JP, Dobson A, Maxwell SL, Coleman K, Starfield BH, Anderson GF: Risk-adjusted Medicare capitation rates using ambulatory and inpatient diagnoses. *Health Care Financing Review*. 17:77-99, 1996.

10) Weiner JP, Starfield BH, Lieberman RN: John Hopkins Ambulatory Care Groups (ACGs): A case-mix system for utilization review, quality assurance and capitation adjustment. *HMO Practice*. 6:13-19, 1991.

11) Weiner J, Starfield B, Steinwachs D, Mumford L: Development and application of a population-oriented measure of ambulatory care case-mix. *Medical Care*. 29:452-461, 1991.

MANAGED CARE EXPERT WORK GROUP ON QUALITY OF CARE

1) Brook RH, Kamberg CJ, McGlynn EA: Health system reform and quality. *Journal of the American Medical Association*. 276:476-480, 1996.

2) Center for Quality of Care Research and Evaluation: *Conquest 1.0: A COmputerized Needs-oriented QUality measurement Evaluation SysTem*. Boston, MA: Harvard School of Public Health, 1996. (Request from Center for Quality of Care Research and Education, Harvard School of Public Health, Boston, MA 02115; Phone 617-432-3270.)

3) The Child and Adolescent Health Policy Center: *MCH Policy Brief: Quality, Quality Assessment, and Quality Assurance Considerations for Maternal and Child Health Populations and Practitioners*. Baltimore, MD: The Johns Hopkins University, 1995. (Request from The Child and Adolescent Health Policy Center, The Johns Hopkins University, 624 North Broadway, Baltimore, MD 21205; Phone 410-550-5443.)

4) Gold M, Felt S: Reconciling practice and theory: challenges in monitoring Medicaid managed care quality. *Health Care Financing Review*. 16:85-105, 1995.

5) Health Care Financing Administration: *A Health Care Quality Improvement System for Medicaid Managed Care*. Baltimore, MD: HCFA, 1993.

6) Ireys HT, Grason HA, Guyer B: Assuring quality of care for children with special needs in managed care organizations: roles for pediatricians. *Pediatrics*. 98:178-185, 1996.

7) Maternal and Child Health Bureau: *A Preliminary Strategy for Assessing Community Systems of Care for Women, Children and Adolescents*. Rockville, MD: MCHB, 1995.

8) McGlynn EA: Choosing chronic disease measures for HEDIS: conceptual framework and review of seven clinical areas. *Managed Care Quarterly*. 4:54-77, 1996.

9) McGlynn EA, Halfon N, Liebowitz A: Assessing quality of care for children: prospects under health reform. *Archives of Pediatric and Adolescent Medicine*. 149: 359-368, 1995.

10) Monahan C, Harder-Shanahan R, Maloney M, Song J: *Quality Community Managed Care: A Guide for Quality Assurance Measures for Children with Special Health Care Needs*. Chicago, IL: The University of Illinois at Chicago, 1996 (draft). (Request from The University of Illinois at Chicago - Division of Specialized Care for Children, 1919 W. Taylor Street, 8th Floor, Chicago, IL 60612; Phone 312-996-1360.)

11) National Academy for State Health Policy: *In QARI: Quality Assurance Reform Initiative Experience in Medicaid Managed Care*. Portland, ME: NASHP, 1994. (Request from the National Academy for State Health Policy, 50 Monument Square, Suite 502, Portland, ME 04101; Phone 207-874-6524.)

12) National Association of Children's Hospitals and Related Institutions. *Pediatric Excellence in Health Delivery Systems*. Alexandria, VA: NACHRI, 1996. (Request from NACHRI, 401 Wythe Street, Alexandria, VA 22314; Phone 703-684-1355.)

13) National Committee for Quality Assurance: *Medicaid HEDIS*. Washington, DC: NCQA, 1996. (Request from NCQA, 2000 L Street, NW, Suite 500, Washington, DC 20036; Phone 202-955-3500.)

14) New England SERVE: *Enhancing Quality: Standards and Indicators of Quality Care for Children with Special Health Care Needs*. Boston, MA: New England SERVE, 1989. (Request from New England Serve, 101 Tremont Street, Boston, MA 02108; Phone 617-574-9493.)

15) Newacheck PW, Stein REK, Walker DK, Gortmaker SL, Kuhlthau K, Perrin JM: Monitoring and evaluating managed care for children with chronic illness and disabilities. *Pediatrics*. 98(5), 1996.

16) Plaut TF, Howell T, Walsh S, Paster M, Jones T: A systems approach to asthma care. *Managed Care Quarterly*. 4:6-18, 1996.

MAKING MEDICAID MANAGED CARE WORK

An Action Plan for People Living with HIV

PRODUCED BY
The National Association
of People with AIDS

WRITTEN BY
Jeffrey S. Crowley, M.P.H.

WITH THE GENEROUS SUPPORT OF
The Henry J. Kaiser Family Foundation

FEBRUARY 1997

ACKNOWLEDGMENTS

NAPWA wishes to acknowledge the important contribution to this report made by all participants in the Seattle meeting. Fifteen Medicaid beneficiaries from 11 states traveled to Seattle to help shape our actio plan. Additionally, 24 others representing a range of government officials, advocates and policy makers who all have a stake in making managed care work for people living with HIV were gracious enough to devote their time to helping us examine many very important issues. In particular, we would like to thank our presenters and moderators: George Beaulieu, Ronald Brunner, Jackie Bulczak, Paul DiDonato, Kathy Foley, Grace Gines, Beri Hull, Neva Kaye, Christine Lubinski, Miguelina Maldonado, Donald Minor, Jeff Stryker, and Tim Westmoreland. Craig Wilkinson, of NAPWA, was instrumental in taking care of all logistics for the meeting and coordinating all activities in Seattle. In addition to the participants, Susan Dooha and Tony Dreyfus also contributed significantly to improving this report. Finally, we would like to thank Dr. Mark Smith and The Henry J. Kaiser Family Foundation for their support and guidance throughout this project.

MEETING PARTICIPANTS

Michael D. Shriver, Facilitator

John Manuel Andriote, Washington, DC
A. Cornelius Baker, Washington, DC
George Beaulieu, Waubun, MN
Ronald Brunner, Los Angeles, CA
Jackie Bulczak, Woodstock, IL
Frank Burgos, Bronx, NY
Donald Chamberlain, Seattle, WA
Mark Cloutier, Berkeley, CA
Jeffrey S. Crowley, M.P.H., Washington, DC
Paul DiDonato, J.D., San Francisco, CA
Brian Eastep, Phoenix, AZ
Brett Paul Evans, New Orleans, LA
Tamora Ferrell, Bronx, NY
Kathy Foley, R.N., Boston, MA
Grace Gines, Worcester, MA
Tracey Gooding, Seattle, WA
Joan Holloway, Bethesda, MD
Ernest Hopkins, Washington, DC
Wayne Howard, Seattle, WA

Beri Hull, Washington, DC
Steve Johnson, Seattle, WA
Neva Kaye, Portland, ME
Everett Kinney, Yhilo, HI
Mari Kitahata, M.D., M.P.H., Seattle, WA
Brian Knowles, Seattle, WA
Christine Lubinski, Washington, DC
Miguelina Maldonado, Washington, DC
Tim Menard, Seattle, WA
Donald Minor, Johnson City, TN
Joseph O'Neill, M.D., M.P.H., Rockville, MD
Pat Philbin, Burien, WA
Mark Randolph, Washington, DC
Christa Singleton, M.D., Washington, DC
Jeff Stryker, San Francisco, CA
Timothy Westmoreland, J.D., Washington, DC
Craig Wilkinson, Washington, DC
Terry Winter, R.N., M.P.H., Santa Rosa, CA
Art Zerbe, Deerfield Beach, FL

EXECUTIVE SUMMARY

On Saturday, July 13, 1996 and Sunday, July 14, 1996, the National Association of People with AIDS (NAPWA) convened a meeting in Seattle, Washington to examine the on-going transition that is taking place within many state Medicaid programs. Increasingly, states are transforming their Medicaid programs from operating under fee-for-service payment arrangements into capitated managed care programs. Meeting participants included people living with HIV from across the nation who are beneficiaries of the Medicaid program, along with federal policy makers, advocates, managed care providers and other experts. The goal of this meeting was to discuss the ramifications of Medicaid managed care for people living with HIV and to devise an action plan that encourages people living with HIV to learn about and actively influence the development of managed care systems that can effectively serve them. The meeting and this report were made possible by the generous support of The Henry J. Kaiser Family Foundation. The outcome of the meeting was consensus on the following nine points:

1. Medicaid managed care is increasingly becoming the reality for people living with HIV. To protect high quality health care, it is necessary to accept that managed care is here to stay.
2. Consumers must be partners with Medicaid programs and managed care providers in the development and monitoring of managed care systems serving people living with HIV.
3. There is a huge need to educate consumers about managed care. This education should address the unique needs of people living with HIV and the challenges posed by managing HIV care.
4. People living with HIV, and their advocates, need to take action at the state level.
5. The HIV epidemic disproportionately impacts many so-called special populations. To successfully meet the needs of people living with HIV, the requirements of people of color, gay men and lesbians, substance users, people with hemophilia, persons in need of mental health services, and individuals from traditionally underserved communities must be an important component of any managed care program serving these individuals.

6. People living with HIV, and their advocates, must push Medicaid programs to more effectively monitor and evaluate managed care plans. This includes using outcome measures related to HIV care and working to establish feedback loops to enable managed care providers to learn about and correct problems in the delivery of health care.
7. People living with HIV must be active in setting priorities for the design of managed health care systems.
8. People living with HIV should strive to work with state Medicaid programs and managed care plans to create incentives that reward the beneficiary, the provider and the managed care plan for improved health.
9. People living with HIV, and their advocates, must advocate for managed care programs that provide high quality care uniformly, despite barriers to accessing care such as language, geography and disability status.

This report describes how to translate these principles into meaningful action on behalf of people living with HIV. It also provides factual information about Medicaid and managed HIV care, as well as a glossary of terms and a resource listing of organizations conducting policy or advocacy work related to Medicaid managed care for people living with HIV.

Individual copies of this report may by obtained free of charge by calling the Kaiser Family Foundation Publication Request Line at (800)656-4KFF. Additionally, the report may be downloaded from NAPWA's Web Site at http://www.thecure.org. Questions about the contents of this report may be directed to Jeff Crowley at NAPWA, (202)898-0414.

INTRODUCTION

Medicaid is the largest form of public support for people living with HIV.

Roughly half of all adults living with advanced HIV disease (commonly known as AIDS) and more than ninety percent of children living with HIV depend on Medicaid during some stage of their illness. Until recently, however, the AIDS community did not devote much attention to advocating for Medicaid. In some regards, Medicaid is a program that people living with HIV "love to hate." The eligibility requirements are such that most adults living with HIV do not qualify for benefits until they have been impoverished by AIDS-related costs and have met the Social Security Administration's criteria for being considered disabled. Although a significant number of people qualify for Medicaid on the basis of receiving cash assistance benefits, thousands of people living with HIV are left without access to health care early in the course of their illness when they do not yet meet the Social Security disability requirements. Some people living with HIV, and their advocates, have suggested that Medicaid is a program that did not need the concerted support of the AIDS community because of its size and the wide range of persons who benefit from the program.

Over the past two years, people living with HIV, and their advocates, have received a wake-up call. Reforms have been proposed (but not yet enacted) at the federal level with the potential to fundamentally alter the structure of the Medicaid program. Some reforms would remove the current federally defined individual entitlement to services for all who meet the program's eligibility requirements. This would be replaced by a fixed federal block grant payment to the states. States would then be given broad new flexibility to operate their Medicaid programs as they choose. Other reforms would redefine eligibility standards in such a way that even fewer people living with HIV would qualify for Medicaid. Still other reforms would undermine existing consumer protections within the federal Medicaid law. Without these protections, beneficiaries would lose access to vital services. Concurrently, state Medicaid programs have been racing to catch up with the private sector in embracing managed care as a cost-containment strategy.

INTRODUCTION

Managed care is a way of providing health care that seeks to integrate the medical care delivery system (including doctors, nurses, hospitals, laboratories, and other providers of health care services) with the insurance system that finances health care. One of the shortcomings of the traditional fee-for-service system is that it enables relatively healthy consumers to inappropriately access health care services which provide them with no clear benefit. This over-utilization of health care services has fueled a high rate of health care inflation. Managed care seeks to limit increases in health care costs by making consumers and providers sensitive to, and jointly responsible for, health care costs.

Medicaid managed care has the promise of providing very good models for the management of HIV disease that rival the quality of care that most people receive in the fee-for-service system. Indeed, well-established managed care organizations such as Group Health Cooperative of Puget Sound and Harvard Community Health Plan have reputations for providing excellent HIV care. Furthermore, several organizations such as the Community Medical Alliance in Boston, Massachusetts and the AIDS Healthcare Foundation in Los Angeles, California are now experimenting with new models for the delivery of HIV care within a Medicaid managed care setting. Ideally, managed care will stress prevention and health promotion as a strategy for avoiding hospital stays and other high-cost health care services. This would translate into the aggressive use of prophylactic treatments resulting in an improved quality of life for many individuals. Managed care organizations also have been more willing than many fee-for-service plans to offer a continuum of coordinated benefits and comprehensive services.

Managed care, by placing providers at risk for the costs of providing health care while also lowering their payment rates, has shifted many of the financial incentives in the health care system. The experience of some, and the fear of many, is that managed care creates incentives simply to deny access to care or to inappropriately limit services needed by sick people. For people living with HIV, this is quite literally a matter of life and death. It is unlikely that the average Medicaid beneficiary (who already experiences many barriers to receiving high quality care in the fee-for-service system) will readily adapt to this new and even more complex health care environment. Educating people about how to survive in this new system is imperative.

Existing protections in the Medicaid law are insufficient because their enforcement relies on the federal government's oversight of state Medicaid programs. While this relationship remains important, it does not address the very critical relationship between a state Medicaid program and the managed care organizations with which it contracts to provide health care services. Indeed, it is through working with state Medicaid programs to influence the contracting process and to monitor the implementation of managed care contracts that people living with HIV can have the greatest impact on protecting high quality health care.

INTRODUCTION

People living with HIV, and their advocates, can be proud of their history of activism in fighting for access to health care. We have shown a willingness to be vocal on Capitol Hill and in the streets to get our community's health care needs met. With all of its shortcomings and limitations, we must value Medicaid as the main source of health care for most people with AIDS; we must continue the legacy of direct involvement of consumers of health care services with policy makers and health care providers to work toward an improved health care system; and we must rely on the history and experience of people living with HIV to devise managed care systems that provide people living with HIV and other beneficiaries with high quality health care.

MEDICAID OVERVIEW

Medicaid is our nation's primary health care safety net for low-income individuals. It is a program that was established in 1965 under Title XIX of the Social Security Act. Unlike Medicare, which is operated solely by the federal government, Medicaid is a federal-state program administered separately in each state. The federal government contributes a matching percentage of state Medicaid outlays, paying a minimum of 50% of health care costs and in some cases paying up to 83% of costs, depending on the state.

In 1995, approximately 36 million Americans (more than one in ten) received health care benefits from Medicaid. In that same year, the total estimated operating cost for the Medicaid program was $156.3 billion.

Medicaid beneficiaries fall into four main categories: low-income children who generally receive cash assistance benefits, certain parents of children receiving cash assistance benefits, low-income elderly individuals who require long-term care, and blind and disabled individuals. Elderly, blind and disabled beneficiaries comprise the smallest categories of beneficiaries, yet they are largely responsible for Medicaid's costs. Most adults living with AIDS qualify for Medicaid on the basis of meeting the income requirements and being disabled. Most children living with HIV qualify for benefits as recipients of cash-assistance benefits [formerly AFDC benefits; now temporary assistance to needy families (TANF) benefits)].

Medicaid covers a range of mandatory services that all states must provide, and an additional range of optional services that states can elect to provide. Mandatory services include inpatient and outpatient hospital, physician, laboratory, x-ray, nursing home and home health services. Optional services include prescription drug benefits (which all Medicaid programs currently elect to provide), clinic services, and prosthetic devices.

SOURCES: *Medicaid Facts*, The Kaiser Commission on the Future of Medicaid, 1995 and 1996.

CONSENSUS FOR ACTION

In examining issues related to Medicaid managed care, agreement was reached on **nine** key consensus points that can serve to guide the actions of people living with HIV:

1

Medicaid managed care is increasingly becoming the reality for people living with HIV. To protect high quality health care, it is necessary to accept that managed care is here to stay.

In talking about managed care for people living with HIV, it is very easy to focus only on the problems that many people face in getting the services they need. It is understandable that some people respond to this by advocating against managed care. By looking at the factors that have caused public and private health care programs to embrace managed care, it is difficult to believe that any level of advocacy will prevent health care from being managed. Over the past few decades, health costs have increased at a rate of inflation greater than that of other goods and services. Our nation spends a growing portion of its resources (when measured as a percentage of the gross domestic product) on health care, and we already spend far more for health care per capita than any other nation.

We do not believe that working against managed care is a useful strategy for protecting high-quality health care for people living with HIV. Instead, we believe that people living with HIV, and their advocates, should recognize the legitimate problem of unconstrained cost increases that managed care is meant to address while also working strenuously to highlight the problems of access to care that are often made worse by managed care. We believe that people living with HIV and all Medicaid recipients benefit when real improvements are made in the efficient delivery of health care services, and resources are reinvested in expanding or improving health care services.

Accepting managed care as a ~~reality does~~ not mean that people living with HIV must accept poor quality or inadequate care. Rather, it means that the efforts of people living with HIV, and their advocates, should be focused on learning how managed care works and on seeking ways to improve managed care programs. This should include efforts to develop financing mechanisms that support the continued viability of many of our current AIDS service organizations and the AIDS care infrastructure that our community has worked to build over the past fifteen years. People living with HIV need to become sophisticated participants in managed care programs in order to hold state Medicaid programs and Medicaid managed care plans accountable for providing optimal quality care.

MEDICAID AND AIDS CARE

Medicaid is the single most important health care program for people living with HIV. In 1994, Medicaid provided seven of ten public dollars for HIV/AIDS care.

An estimated 90,000 people with AIDS (or approximately 53% of people then living with AIDS) received Medicaid benefits in 1994. Additionally, roughly 90% of all children living with HIV disease depend on Medicaid for their health care. Despite the clear dependence of the AIDS community on Medicaid, people living with HIV comprised only 0.3% of all Medicaid beneficiaries in 1994. These beneficiaries were responsible for only 2% of total Medicaid costs.

The cost of treating people living with HIV varies greatly depending on a number of factors, including the stage of illness. In 1992-93, the Community Medical Alliance in greater Boston, Massachusetts found that their monthly costs for treating people with HIV disease varied from $793 to $3,600. These costs excluded oral pharmacy benefits which would contribute to much greater variations in cost.

Co-morbid conditions such as mental illness and substance abuse also contribute considerably to variations in total costs for treating people living with HIV.

SOURCES: *Medicaid's Role for Persons with HIV/AIDS*, Kaiser Commission on the Future of Medicaid, 1996; The Medicaid Working Group provided data on the Community Medical Alliance.

2

Consumers must be partners with Medicaid programs and managed care providers in the development and monitoring of managed care systems serving people living with HIV.

Since the early years of the HIV epidemic, people living with HIV, and their advocates, have fought for access to health care and have challenged the notion that patients are merely passive recipients of health care. Rather, we have pushed to help set the nation's research agenda; we have created agencies and structures within our own communities to provide health care; and within Ryan White CARE Act programs, we have insisted upon formalized roles for consumer involvement. In order for Medicaid managed care to meet the needs of people living with HIV, beneficiaries of managed care programs must be involved in all aspects of the design, implementation and monitoring of managed care programs.

CONSENSUS FOR ACTION

Some managed care organizations have historically included beneficiaries on governing bodies or on their boards of directors. Through participating in the governance of organizations, people living with HIV have worked in partnership with managed care organizations. Consumer boards are another way for health care plans to gain input from consumers or to receive technical assistance in analyzing issues. For these boards to work effectively, however, they must be structured to expand their role beyond simply advising and they must be given decision-making authority. In the Medicaid context, given that all beneficiaries have low incomes, it is necessary for the managed care organizations to pay for the costs of beneficiaries to participate on governing or consumer boards.

Consumer boards alone, however, are insufficient. Managed care programs must have well-articulated grievance processes that allow beneficiaries to challenge denials of service or to complain about inappropriate care. Additionally, states must monitor grievance patterns in order to identify and correct on-going problems reported by consumers. States must also support ombuds programs or consumer advocacy initiatives in order to monitor trends or identify and address newly arising access or treatment-related concerns.

Furthermore, it is important to recognize that issues related to parity, inclusion and representation of people living with HIV disease are often difficult to adequately address. A lack of understanding of the diversity of the HIV-affected communities can make it challenging for the mainstream health care system to successfully address the needs of people living with HIV. This is complicated by the difficulties associated with seeking the participation of individuals whose health status frequently changes. People living with HIV must insist upon being partners with state Medicaid agencies and managed care plans. Widespread participation of the HIV-affected communities and other beneficiaries must be a part of all decision-making processes regarding Medicaid managed care programs.

WHAT IS MANAGED CARE?

Managed care involves the integration of the health care delivery system (which includes doctors, nurses, hospitals, laboratories and other health care providers) with the insurance system that finances health care.

Managed care is a health care delivery system that frequently utilizes per capita (or capitated) payment arrangements to physicians, hospitals and other providers in order to conserve health care resources.

3

There is a huge need to educate consumers about managed care. This education should address the unique needs of people living with HIV and the challenges posed by managing HIV care.

In order for people living with HIV to maximize the benefits of managed care, it is important that they understand how this system works. Consumer education is needed to achieve the following five goals:

- **Create informed beneficiaries.** It is necessary to educate consumers about the features of managed care and how best to interact with the system to get their needs met. This should cover basic concepts such as how to select a health plan, how to select a health care provider, when and how to seek out-of-network care, and how to grieve or complain about inadequate care or the denial of health care benefits.
- **Develop strong advocates.** This goal involves educating people living with HIV, and their advocates, about how the Medicaid program works and how managed care programs work. Advocates must understand basic facts about the structure of Medicaid, including how the waiver authority functions that allows states to create mandatory managed care programs. Advocates must also learn about the Medicaid system in their state, including identifying the key health care players such as federal, state, and local officials and legislators, as well as other advocates.
- **Clarify the distinctions between managed care and fee-for-service health care and among managed care plans.** Consumers must gain a better understanding of basic principles of our insurance system. Individuals must be provided information on how to function in a new Medicaid environment. A part of this includes giving consumers information about how to navigate through the system when experiencing difficulties with a provider or a managed care organization, as well as how to make choices when competing benefits are available from various health plans.
- **Improve the evaluation and monitoring of Medicaid managed care plans.** Under the fee-for-service system, a key role for Medicaid advocates was to monitor the federal oversight of state Medicaid programs. If consumers were not receiving the health care services they needed, if poor quality care was being provided, or if eligible individuals were being denied Medicaid benefits, pressuring the federal government to exercise its oversight authority on state Medicaid programs often led to improvements. In the managed care environment, understanding the relationship between the state Medicaid program and numerous managed care organizations has become far more important in order to protect high quality care. People living with HIV need to understand how this new system

works and how they can push states to write strong and enforceable contracts with managed care organizations. Once contracts are signed, people living with HIV, and their advocates, need to become active in the monitoring and enforcement of the contracts.

- **Encourage people living with HIV to form coalitions with other Medicaid beneficiaries.** Success at protecting Medicaid for people living with HIV requires people living with HIV to form broadly based coalitions. A managed care plan that is designed to meet the complex needs of people living with HIV should also be designed to provide high quality care to other beneficiaries. Additionally, people living with HIV should remember that Medicaid is our nation's primary health care safety net, and through our strong and consistent advocacy, we have the power to make this program better for all who depend on it.

ABOUT CAPITATION

What is Capitation?

The basis for most current managed care programs involves paying for health care services with capitated payments, as opposed to paying for health care on a fee-for-service basis. This financing change marks a fundamental shift in the relationships between consumers, payers and providers of health care. Under fee-for-service, the payer (in the Medicaid context, this would be the state Medicaid agency) is largely responsible for all financial risk should a beneficiary become ill. Capitated managed care seeks to save the payer money by utilizing the capitated payment to transfer some of the risk for health care costs from the payer to the health plan or the individual health care provider. Paying for health care involves risk because there is no way of knowing in advance how much health care an individual will require over a given time period.

How Does Capitation Work?

A capitated payment is a payment made to a provider on a per-member, per-month basis. This means that a physician or other provider would receive a payment every month for every patient they have in that managed care plan, whether or not the patient uses any health care services. In agreeing to accept this payment, the provider is agreeing to assume responsibility for the health of her or his patients. The capitated payment from one patient may not be sufficient to cover the health care costs of that individual patient. By pooling the capitated payments from every patient, it is anticipated that the provider can pay for all necessary health care expenses, as well as receive a fair compensation for their own services. This is intended to take away the incentive in the fee-for-service system to over prescribe health care services for healthy people.

Theoretical Basis for Capitation

Ideally, capitation will give the provider the freedom to make health care decisions in the best interest of the patient. If a patient would like a service that the provider does not believe is medically necessary, the provider's own financial risk creates an incentive to deny the patient the service. However, since a provider's costs increase if the patient becomes sick and requires more extensive or more expensive health care services, it should not be in the interest of the provider to deny necessary services. This system presumes that the provider is experienced and knowledgeable about all types of illness, and is capable of judging when health care services can be denied without inflicting adverse effects on the patient.

4

People living with HIV, and their advocates, need to take action at the state level.

In the past, problems with Medicaid could often be addressed at the federal level. As Medicaid programs adopt managed care systems, the importance of influencing the development of contracts between state Medicaid programs and individual managed care providers (and monitoring their enforcement) shifts much of the action to the state level. To protect the quality of their health care, people living with HIV should take the following actions:

1. Identify and join state-level coalitions or create new coalitions of people with disabilities, advocates for children, the elderly and others organized at the state level who depend on Medicaid for their health care.
2. Critically examine the status of Medicaid in a particular state, and set clear and specific priorities for consumer involvement.
3. Learn who the key players are in a particular state and develop relationships with them.

Concerns with Capitation

A real problem with capitation for people living with HIV is that too many practitioners are extremely inexperienced with providing HIV care, and are in no position to rationally weigh when a particular service is, or is not, needed. This problem is made worse in managed care organizations where non-health care personnel are involved in authorizing treatment. In many cases, the inexperience of providers within a plan also creates incentives for people living with HIV to switch their enrollment to another plan, as this may be their only way to gain access to an experienced specialist practitioner. For people living with HIV, a very real concern is that the incentive in capitated managed care may be for a provider to allow a patient to get sick and die quickly. Because the provider's own profit declines with every new service that a sick person needs, the fear is that capitation will only lead to the underservice of people living with HIV.

Minimizing Incentives to Deny Care

The Health Care Financing Administration, some state Medicaid programs, and some private philanthropic organizations are currently experimenting with risk adjustment procedures that seek to compensate both managed care organizations and individual providers with a high caseload of people with AIDS. Additionally, others are experimenting with stop loss insurance, risk corridors, and other mechanisms that are designed to limit the financial risk of a provider for an individual patient who has very extensive health care needs.

The capitated payment is a critical element of most current managed care programs.

4. Develop and disseminate a brief guide of the Medicaid managed care issues to be addressed. This can be used to encourage other partners to form a common agenda and can foster cooperation among groups of advocates.

5. Devise an advocacy strategy that will support specific goals and priorities. This strategy may involve lobbying state legislators, working with state Medicaid programs, writing letters to public officials, and using the media to raise public awareness of specific goals.

WHERE IS MEDICAID AIDS CARE BEING MANAGED?

Across the nation, states are seeking federal waivers (exemptions from parts of Title XIX, the federal Medicaid statute) to mandatorily enroll Medicaid beneficiaries into managed care. Since January 1993, the federal Health Care Financing Administration (HCFA) has given 13 states permission to enact statewide Medicaid demonstration projects, 19 states have been granted waivers as part of larger welfare reform programs, and 25 sub-state waivers have been granted.

The following states have received approval to enact statewide Medicaid demonstration projects that would place people with AIDS in mandatory managed care programs: Hawaii, Illinois (approved, but not implemented), Kentucky (approved, but not implemented), Minnesota, Ohio (implemented in July 1996), Oregon, and Tennessee.

Since 1994, the Health Resources and Services Administration (HRSA) has awarded grants under the Ryan White Special Projects of National Significance (SPNS) program to support five grantees to explore the development of new models of HIV care within the managed care environment. Funded projects include: AIDS Healthcare Foundation (Los Angeles, CA); East Boston Neighborhood Health Center (Chelsea, Revere, East Boston, and Winthrop, MA); Johns Hopkins University School of Medicine (Baltimore, MD); New York AIDS Institute (New York State); and the Visiting Nurse Association-Los Angeles (Los Angeles, CA).

SOURCES: Health Care Financing Administration, 1996 and *Issues and Strategies*, Henry J. Kaiser Family Foundation and the Health Resources and Services Administration, 1996.

5

The HIV epidemic disproportionately impacts many so-called special populations. To successfully meet the needs of people living with HIV, the requirements of people of color, gay men and lesbians, substance users, people with hemophilia, persons in need of mental health services, and individuals from traditionally underserved communities must be an important component of any managed care program serving these individuals.

Communities hardest hit by the HIV epidemic often have been labeled as "special populations." However, these so-called special populations are in fact our neighbors, our families, our friends, our clients, and even ourselves.

Too often, the needs of specific groups of people have been treated as an afterthought for many health care plans. In other words, after health care plans have established their core set of benefits, they then tack on a supplementary (and often inadequate) package of programs to provide mental health, substance abuse treatment, transportation, and other supposedly ancillary services. In reality, these services are essential to the health and well-being of people living with HIV.

These supplementary programs are problematic because the services offered are often underfunded or barriers are erected to limit the use of these services. They are usually not made equally available to all beneficiaries who need them. Generally, the services are also not coordinated sufficiently with other benefits.

In providing HIV care, it is important to understand that all people have some sort of special need. Only plans that seek to coordinate all services, including non-traditional health care services and enabling services, such as transportation, will be able to effectively serve people living with HIV.

LISTENING TO THE CONSUMER

The ability of managed care to succeed in serving people living with HIV is dependent upon its ability to listen to and respond to the need of its beneficiaries.

Donald Minor can't wait for care.

As a person living with HIV who is also a person with hemophilia, he has experienced utilization review (a practice of managed care organizations such as requiring prior approval before they will pay for a procedure or service) and other managed care practices that can lead to a delay or denial of care. "I'm really what is called a moderate to mild [person with hemophilia]. But when I have an episode, it can't wait for a 10-day clearance, because I could die waiting for somebody to pick up the telephone to say, 'You've got the okay, go ahead and get your medicine.' I have to have my medicine with me ALL of the time. When I start to bleed, I have got to treat it immediately or I suffer the consequences."

Grace Gines knows how important it is to have educated health care practitioners.

As a woman living with HIV, she recalls the challenges she has faced in getting adequate gynecological care. She recounts that she was in a managed care program where she received most of her primary care in an infectious disease clinic, but was referred out for specialty care, including routine gynecological care. She recalls facing discrimination from the gynecologists because many did not want to treat her. Then, when she was treated, she received routine care (such as a pap smear) that was inadequate. "The doctor said I was fine, and she gave me a referral for another appointment in a year. I know that a woman with HIV should have a pap smear every six months. I didn't really confront her. I didn't have the energy. I didn't feel like educating her." Grace did go back to her nurse practitioner, who was her primary care provider, and explained the problem. Thereafter, her nurse practitioner arranged for a pap smear every six months. Grace highlights the importance of regular pap smears and other screenings for women with HIV. Pelvic inflammatory disease (PID) and other gynecological problems are far more common in women living with HIV than in other women. Like most Medicaid beneficiaries, Grace didn't know the best way to complain or take action.

Historically, managed care health maintenance organizations (HMOs) have serviced largely healthy populations. Grace's experience also highlights the problem that many managed care organizations have not contracted with a broad enough range of specialist providers to meet the needs of people living with HIV who have very complex health care needs.

Beri Hull is worried that her doctors will not know what to do to help her stay in recovery.

Beri is a former heroin user who is in recovery and living with HIV. She has concerns that existing barriers to people simply entering the health care system will become worse under managed care, and she worries that substance users who take the first step to recovery will be prevented from getting the care they need by being kept on waiting lists to receive treatment. Ten years ago, Beri was an active substance user in Chicago. She was on Medicaid, but she didn't even know which health care services she was entitled to receive. "I got on general assistance. I wanted the $150 a month that they gave us. We called it a green card back then. I was barely aware that I had health care services along with this. I was a person who avoided doctors and establishments if I possibly could."

Beri tells of becoming sick and needing to be hospitalized. Because she was concerned that people would come after her for payment, she gave a false name. She explains that she was so distrustful of doctors and hospitals that she never thought about seeking information on services she could receive. "I think my experience is not unique. So I want to know how managed care is going to affect a person who may not even know they're on managed care."

Beri's experience illustrates the need for managed care organizations to expand their capacity to provide substance abuse treatment. It also shows how important it is to have a provider who understands her perceptions of doctors and the health care system in order to help get her health care needs met.

George Beaulieu is concerned about access to care.

George lives in rural Minnesota. He has found it difficult to locate an experienced HIV practicioner who is geographically accessible. The nearest doctor is 40 miles away, but this provider is not knowledgeable of HIV care. Out of desperation, George has resorted to traveling to Minneapolis, more than 200 miles away, to receive his health care. There, the Hennepin County Medicaid program provides him with comprehensive services.

George's problem in finding an experienced HIV provider is shared by many persons living in rural areas. It also underscores the importance of Medicaid managed care organizations developing mechanisms for obtaining out-of-network, specialty care that do not impose additional cost-sharing burdens on the beneficiary.

LISTENING TO THE CONSUMER

CONSENSUS FOR ACTION

6

People living with HIV, and their advocates, must push Medicaid programs to more effectively monitor and evaluate managed care plans. This includes using outcome measures related to HIV care and working to establish feedback loops to enable managed care providers to learn about and correct problems in the delivery of health care.

As managed care organizations focus increasingly on cost containment, people living with HIV need to be at the forefront of efforts to create new monitoring systems and enforcement mechanisms to ensure that individuals receive a broad range of services. Consumer surveys and practitioner surveys are important tools that managed care organizations should use to gain information about positive and negative aspects of their health care delivery program.

A key priority for people living with HIV is the development of specific health outcomes that can be used to measure the quality of health care within a plan. Unfortunately, one of the problems experienced by many Medicaid managed care programs is that the states' own information systems are often antiquated. As a result, state Medicaid programs do not even ask for the type of information that is needed to compare the performance of health plans or to identify problems in the delivery of health care. This problem is exacerbated by gaps in data provided by plans and lack of sufficient infrastructure, including staff and resources, to review data that managed care organizations provide to state Medicaid agencies.

TYPES OF MANAGED CARE ORGANIZATIONS

Many types and variations of managed care organization currently exist. While structure may vary, one of the key distinguishing factors among managed care organizations is the level of risk they assume for providing health care services.

No Risk: Primary Care Case Management Organizations (PCCMs) often contract directly with a state Medicaid program to serve as the gatekeeper. They monitor and approve virtually all covered services, and are paid on a fee-for-service basis. They generally assume no risk for the provision of health care services.

Limited-Risk: Prepaid Health Plans (PHPs) either contract on a pre-paid capitated-risk basis to provide a specific set of services (limited risk) or they contract on a non-risk basis. One type of PHP arrangement is for an organization to sign a contract with the state to accept a capitated payment from the state Medicaid program to provide only ambulatory care services. A managed care organization is considered to be at limited risk if it is not required to provide comprehensive services, but its risk is limited to a defined set of benefits.

Full-Risk: Health Maintenance Organizations (HMOs) are fully capitated. These managed care organizations are paid a per-member, per-month fee in exchange for providing a comprehensive range of services. These plans are considered full risk because they are responsible for delivering all medically necessary services.

SOURCE: *Medicaid Facts*, The Kaiser Commission on the Future of Medicaid, 1996.

7

People living with HIV must be active in setting priorities for the design of managed health care systems.

In order for any managed care program to provide high quality HIV care, it must have in place structures that enable it to articulate what should be happening in the delivery of health care, assess what is really happening, and fix any problems.

Putting in place strong **access standards and clinical guidelines** are important ways to tell the managed care organization what it should be doing with regard to HIV care. Access standards should cover issues such as normal waiting times for an appointment, the maximum distance a beneficiary must travel to seek care, standards for the number of in-network specialists over a broad range of medical disciplines that a plan must keep as a proportion of the enrolled population, and time limitations within which a plan must resolve any outstanding consumer grievances.

The standard for high quality HIV care is changing rapidly. New treatments and treatment protocols are becoming available every few months, and each new day brings an increased understanding of how to use drugs and other therapeutic tools to maintain health. Access standards define what kind of care a plan must deliver. These standards must be seen as an evolving floor, or a minimum level of care that a managed care organization is expected to provide. People living with HIV, and their advocates, should always work to raise both the ceiling of what level of HIV care is optimally possible and the floor of what minimum level of care is expected for everyone.

CONSENSUS FOR ACTION

Clinical guidelines are specific recommendations that a plan makes to a provider regarding what constitutes high quality HIV care. They include recommendations for assessing when it is necessary to refer an individual to a specialist, when a provider should recommend prophylaxis for opportunistic infections, when to offer antiretroviral therapy, when to switch regimens, and when to provide diagnostic services such as viral load testing.

In order to know what is actually happening within a managed care organization, sophisticated **management information systems** are necessary. Management information systems involve setting up record keeping systems that enable a managed care organization to track the composition of its beneficiaries, the services they are receiving, which services are costing the most money, and assess the ultimate impact on the health of the beneficiaries of various treatment options.

Once a monitoring system has been developed, and expectations have been established for what a managed care organization should be doing, **process and outcome measures** help to track what is happening. Process measures look at issues such as how often a beneficiary is offered a specific

A MODEL MANAGED CARE PROGRAM

The Community Medical Alliance, Boston, MA

Since 1989, the Community Medical Alliance (CMA) has operated a managed care program for people with severe physical disabilities. In 1992, this program was expanded to cover people with AIDS. Whereas most managed care programs seek to avoid people living with HIV and other high cost beneficiaries, CMA has actively recruited people with AIDS.

CMA's model of care is based on using teams of nurse practitioners and physicians to coordinate and provide primary and acute care services. CMA receives three capitated rates from Massachusetts Medicaid. One rate covers people in the advanced-stage AIDS program and is the highest payment. The next rate covers people in the severe physical disability program, which primarily covers people with quadriplegia. The third payment rate is for any Medicaid recipient with a disability who does not qualify for one of the other two rates, including some people living with HIV.

service. For example, pneumocystis carinii pneumonia (PCP) is one of the most common opportunistic illnesses experienced by people living with HIV, despite the fact that most cases of PCP are easily preventable with low-cost antibiotics. An important process measure that can shed light on the quality of HIV care within a plan involves how often or when an HIV positive beneficiary is offered PCP prophylaxis. These types of measures are useful in indicating whether or not appropriate services are being routinely provided.

Outcome measures are more difficult to assess, but are often more useful than process measures They are designed to indicate if the health care intervention has resulted in improved health. An example of an outcome measure in the case of PCP would be information that tracks how many people living with HIV within a health plan are hospitalized for PCP. A managed care plan that can show that its HIV-positive beneficiaries are hospitalized with PCP less frequently than beneficiaries in another plan (at a comparable stage of disease progression) can use this to argue that it is providing higher quality care. This type of measure is also useful for indicating the relative effectiveness of different types of interventions.

Mental health, substance abuse treatment, home health and other services are contracted out by CMA, but are part of the capitated payment. Services not included in the capitated rate, such as outpatient pharmacy, dental care, and optometric care are reimbursed by Massachusetts Medicaid on a fee-for-service basis.

An important component of the CMA model is that various financial arrangements are employed to limit their financial risk. For the advanced-stage AIDS program, this includes stop-loss insurance that covers 75% of inpatient costs over $45,000 per beneficiary, in a given year. The premium that CMA pays for this insurance is deducted from the capitated rate they receive from Massachusetts Medicaid. Similar risk-limiting arrangements with different thresholds, premiums, and reimbursement levels are also in place for their other two capitated rates.

The CMA program remains very small. It currently has fewer than 500 enrollees, approximately 100 of whom are people living with AIDS. While critics will point out that CMA has not been able to demonstrate that it can provide care less expensively than fee-for-service Medicaid, proponents argue that CMA's caseload involves people with far more advanced AIDS than the general Medicaid population. As advocates, we are looking for models of high quality Medicaid managed care, and CMA has been able to demonstrate that incidence of PCP (a potential marker for quality) dropped significantly following enrollment in CMA's program.

SOURCES: *Delivering HIV Care in a Managed Care Environment: Issues and Strategies*, Kaiser Family Foundation and the Health Resources and Services Administration, 1996; and the Community Medical Alliance.

CONSENSUS FOR ACTION

Once a comparison is made between what should be happening in a managed care plan and what actually is happening, it becomes necessary to change practices and procedures. Filing a grievance is one important way for an individual consumer to address shortcomings in the delivery of their health care. A grievance is a formal complaint that a beneficiary may file with a managed care organization or with the state Medicaid agency.

For example, if a beneficiary has been told that the managed care organization will not pay for them to receive viral load testing, the beneficiary may argue that this test is necessary to establish a baseline of their immune functioning from which to monitor the progression of their illness and the effectiveness of treatment. They can look for studies to show that such a test is the current state of the art in assessing disease progression. Complaining can force the managed care organization to review its decision not to provide the viral load test. In many cases, this can lead to a reversal of the previous denial of the service.

Another approach to solving problems in the managed care system is to establish an **ombuds program**. An ombudsperson is someone either inside or outside of the managed care organization (preferably outside of the organization so that they are completely independent of the health plan) who receives grievances and attempts to work with both parties to resolve a grievance. In many models, the ombudsperson often functions as a beneficiary advocate. Many advocates have recently shown a renewed interest in ombuds programs.

TIM'S LIST

Tim Westmoreland has a vision for Medicaid advocates. As someone who was worked on Medicaid and AIDS Issues on Capitol Hill for more than a decade, he has a clear perspective on what people living with HIV, and their advocates, should be doing to protect high quality health care. Tim believes that Medicaid advocacy should focus on the following five priorities:

1. **Make sure managed care organizations get paid enough.** While it may seem counter-intuitive to worry about how much a for-profit health care plan gets paid, he says that this is the best way to ensure that people living with HIV get the care they need. Tim believes we can get managed care organizations to provide high quality care if we make sure that Medicaid is paying them for high quality care.
2. **Protect existing categorical eligibility.** The best health care system is worthless unless people can get in the door. Therefore, an important goal of any advocacy effort must be to ensure that the current federal defini-

8

People living with HIV should strive to work with state Medicaid programs and managed care plans to create incentives that reward the beneficiary, the provider and the managed care plan for improved health.

We are currently living in a time of considerable optimism that our nation's investment in biomedical research has begun to pay off with a series of new drugs (protease inhibitors and other antiretrovirals) that show great promise in successfully treating HIV disease. This has caused many people living with HIV to consider a whole range of new possibilities. Improved health due to these therapies could even permit some people who were previously disabled to return to work.

Due to the nature of our health care system, and the fact that most adults with AIDS only qualified for Medicaid coverage once they were too ill to be "gainfully employed", the new treatments could be so effective in restoring health that they make the individual ineligible for Medicaid. This could threaten access to the drugs that are necessary to maintain their newfound vigor. One of the main features of managed care is that physicians and other providers who receive a capitated payment are at risk for the cost of their patient's health care. An important advocacy goal must be to ensure that Medicaid managed care programs are designed such that people living with HIV, their health care providers, and their managed care organizations all benefit from the individual becoming healthier.

tion of disability is maintained as a floor, and that other eligibility categories are protected.

3. **Make sure that the managed care contract covers the right set of benefits.** We live in an era of cost constraint and growing limitations on covered health care services. Therefore, an important issue for people living with HIV regards priorities for covered services. Many people with HIV recognize the prime importance of prescription drug benefits. Beyond drug benefits, consumers and advocates need to set priorities to make sure that managed care contracts cover the services that people really need.
4. **Work for tough quality assurance standards, including the use of outcome measures.** The best health care program, on paper, will not help people in the real world unless strong quality assurance systems are in place. This requires managed care organizations to set goals for quality improvement and it also entails a strong data collection and evaluation program to assess what is, and is not, working. Outcome measures that look for improved health are an important way for managed care organizations to show that they are providing high quality health care.
5. **Make sure that enforcement mechanisms exist to ensure that beneficiaries receive the care for which they qualify.** Enforcement of the Medicaid law and enforcement of the managed care contract are two critical elements of a well functioning Medicaid program. Without strong enforcement structures, beneficiaries will not receive the care they need.

Timothy M. Westmoreland, J.D. is presently a Senior Policy Fellow at the Georgetown University Federal Legislation Clinic in Washington, D.C. For many years, he worked as counsel to the House Commerce Committee's Subcommittee on Health and the Environment under Chairman Henry Waxman. The views presented here are his own, and not necessarily those of his employers or associates.

CONSENSUS FOR ACTION

9

People living with HIV, and their advocates, must advocate for managed care programs that provide high quality care uniformly, despite barriers to accessing care such as language, geography and disability status.

A concern about Medicaid managed care is that not all beneficiaries are situated to speak up when they experience difficulties in getting the care they need. Because of the ways in which managed care changes many of the financial incentives in the health care system, Medicaid must strengthen the existing mechanisms to ensure that all beneficiaries are treated uniformly and fairly.

A CRITICAL ISSUE: FOCUSING ON THE MANAGED CARE CONTRACT

Neva Kaye is the Operations Manager at the National Academy for State Health Policy, an organization that provides technical assistance to state Medicaid programs. Previously, she has also worked in the Medicaid Administration in Wisconsin.

Neva believes that the development of a strong Medicaid managed care program for people living with HIV depends on having an enforceable contract with clear and measurable responsibilities between a state Medicaid agency and the managed care organization. While the following is not an exhaustive list, she stresses that any contract must:

1. Define **medical necessity** and describe the circumstances when the plan is required to provide all medically necessary services.
2. Provide for a broad range of **covered services.**
3. Address how a managed care organization will ensure that all covered beneficiaries are able to **access** health care services.
4. Articulate permissible and impermissible **marketing activities and enrollment procedures.**
5. Outline **quality assurance** activities that a plan must undertake.
6. Define the **grievance and appeals process.**
7. Specify the types of **data** that a managed care organization must report to the state. This should include data collection requirements pertaining to the utilization of health-care services, health care outcomes, and financial operations of the managed care organization.

Under current Medicaid law, all Medicaid services must be provided without regard to the disease status of the beneficiary. Other provisions of the law require all services to be provided statewide and insist that the services that one type of beneficiary receives must be comparable to those that another receives. Still other provisions of the Medicaid law guarantee beneficiaries all medically necessary services.

It is important to recognize that great variations in language, culture, geography, and other factors exist that have the potential to divide the AIDS community. However, high quality health care for any beneficiary is threatened unless high quality health care is ensured for all beneficiaries. Therefore, an important goal of our advocacy must be to ensure that all people are treated fairly in Medicaid managed care programs and that all people receive the high quality health care that everyone deserves.

8. Define the geographic **service area** of the managed care plan.
9. Describe how and when a beneficiary may **select a primary care provider.** This should describe the circumstances when a beneficiary may insist that a specialist provider be designated the primary care provider.
10. Outline and limit **cost-sharing requirements** for beneficiaries.
11. **Prohibit discrimination,** and provide for specific civil rights protections for beneficiaries.
12. Describe and limit permissible **utilization review** techniques.
13. Define and disclose information about **relationships with providers.**
14. Describe **enforcement** of the contract and provide for **sanctions for non-compliance.**
15. Define the **term** of the contract and provide **conditions for termination.**
16. Address issues related to beneficiary **confidentiality** and confidentiality of medical records.

Note: Several organizations listed in Appendix B are able to provide or help direct individuals to technical assistance on managed care contracts, including the National Academy for State Health Policy.

APPENDIX A

Glossary of Terms

Beneficiary — Person who has Medicaid coverage.

Capitated Payment — Payment to a physician, hospital, or other provider made on a per-member (of a health plan) per-month basis, whether or not the individual uses health care services during that month.

Carve Out — Practice of excluding specific services from a managed care organization's capitated rate. In some instances, the same provider will still provide the service, but they will be reimbursed on a fee-for-service basis. In other instances, carved out services will be provided by an entirely different provider. Because of great variations in cost from one patient to the next, HIV care, mental health services, and substance abuse treatment are types of services that are often carved out.

Co-Payment — A fixed fee that the beneficiary must pay out-of-pocket each and every time they access a particular health care service.

Deductible — The amount of out-of-pocket expenses that a beneficiary must pay before the insurance plan will begin to cover its share of the health care costs.

Fee-for-Service — The traditional style health delivery system in which a beneficiary can choose their own provider and the insurance company is responsible for paying a specific portion of the fee for each and every service.

Formulary — A list of drugs that an insurance company or managed care organization agrees to provide to their beneficiaries, when prescribed by their health care provider. Drugs not on the formulary are not covered by the health plan. The use of formularies is a cost-containment strategy employed by some managed care organizations to limit access to high-cost medications.

Gag Clause — A provision of a contract between a managed care organization and a health care provider that restricts the amount of information a provider may share with a beneficiary or that limits the circumstances under which a provider may recommend a specific treatment option.

Gatekeeper — A person employed by a managed care organization (generally a primary care physician or a case manager) responsible for monitoring and coordinating a beneficiary's health care. This individual must pre-approve specific services and referrals to specialist providers in order for the managed care organization to accept responsibility for paying for the care provided.

Grievance — A complaint about denial of care, inappropriate care, or other problem that is lodged by a beneficiary against their health care plan.

Group Model HMO — A type of health maintenance organization that operates a closed network of providers who are generally paid on a salaried basis. Unlike a staff model HMO, all of the health care providers are not located in one facility or clinic and the HMO generally does not own their own health care facilities.

Health Maintenance Organization (HMO) — The oldest and most common form of managed care organization in the United States. HMOs are a health care delivery system that accept a pre-paid premium and provide a specific set of benefits and services, generally through a closed network of care providers. (For specific types of health maintenance organizations, see also — Group Model HMO, Independent Practice Association, and Staff Model HMO).

Independent Practice Association (IPA) — A type of managed care organization in which beneficiaries may select from among a list of in-network providers. Providers accept an established capitated payment, but are free to accept patients from more than one managed care organization.

Insurer — A person or organization who receives a premium in exchange for agreeing to provide a certain set of benefits, should an adverse event (such as illness) occur.

Managed Care — An approach to the delivery of health care that seeks to integrate the medical care delivery system (physicians, hospitals and other service providers) with the insurance system that finances health care.

Managed Care Organization (MCO) — A health plan that seeks to manage care. Generally, this involves contracting with health care providers to deliver health care services on a capitated (per-member per-month) basis. (For specific types of managed care organizations, see also Group Model HMO, Health Maintenance Organization, Independent Practice Association, and Staff Model HMO).

Medicaid — A health care program that is jointly operated between the federal and state governments to provide health care to specific categories of low-income residents — cash assistance recipients, persons with disabilities, and the elderly who require long term care.

Medicaid provides health care benefits to more than 50% of all adults with AIDS in the United States (who generally qualify on the basis of disability). Additionally, more than 90% of all children with HIV disease depend on Medicaid for their health care. Most of these children and their parents qualify for coverage because they also receive cash assistance.

Please note that federal welfare reform legislation was recently enacted that eliminates the Aid to Families with Dependent Children (AFDC) program and replaces it with a new type of cash assistance program, called Temporary Assistance for Needy Families (TANF). Nonetheless, children and their parents who would have qualified for benefits under the old AFDC program remain eligible for Medicaid benefits.

Another important source of Medicaid coverage for people with AIDS is the medically needy program. Medically needy persons are those individuals who meet the disability requirements for Medicaid, but whose income is too high to automatically qualify for coverage. Persons may also spend down into the medically needy category whereby they spend their own resources to pay for medical care until their income minus their medical expenses would make them eligible for coverage. Although states are not required to operate medically needy programs, 36 states currently do.

Medicare — A federal health care program providing benefits to elderly retirees and people with disabilities who have a work history that makes them eligible for benefits. Persons under age 65 must be disabled for a period of two years before they qualify for benefits. While this 2-year requirement has traditionally limited access to Medicare for people with AIDS, Medicare now pays for more AIDS care than the Ryan White CARE Act. Additionally, as new treatments and other changes increase our ability to manage HIV disease, Medicare will increase in importance as a source of health care for people with AIDS.

Some people are dually eligible for Medicaid and Medicare.

Network — A list of physicians, hospitals and other providers who provide health care services to the beneficiaries of a specific managed care organization.

Ombudsperson — A person within a managed care organization or a person outside of the health care system (such as an appointee of the state) who is designated to receive and investigate complaints from beneficiaries about quality of care, inability to access care, discrimination, and other problems that beneficiaries may experience with their managed care organization. This individual often functions as the beneficiary's advocate in pursuing grievances or complaints about denials of care or inappropriate care.

Not all states or health plans currently operate ombuds programs. These programs increasingly are being examined by consumer advocates as a mechanism for protecting the interests of beneficiaries within managed care organizations.

Open Season — Period (generally once per year) when persons who have a choice among more than one health plan are permitted to switch enrollment to another plan.

Out-of-Network Provider — A health care provider with whom a managed care organization does not have a contract to provide health care services. Because the beneficiary must pay either all of the costs of care from an out-of-network provider or their cost-sharing requirements are greatly increased, depending on the particular plan a beneficiary is in, out-of-network providers are generally not financially accessible to Medicaid beneficiaries.

Out-of-Pocket Expense — Payments that the beneficiary must pay at the time that they access a particular health care service.

Primary Care Provider — A type of health care provider who is trained to recognize and treat a broad range of medical problems. Primary care physicians are frequently trained in family medicine or internal medicine.

In the context of managed care, the primary care provider often serves as the gatekeeper who must approve all referrals to specialist providers.

Private Insurance — Health insurance that is operated by the private sector. Any health insurance plan not operated by federal, state or local governments.

Re-insurance — A method of limiting the risk that a provider or managed care organization assumes by purchasing insurance that becomes effective after set amount of health care services have been provided. This insurance is intended to protect a provider from the extraordinary health care costs that just a few beneficiaries with extremely extensive health care needs may incur. (See also stop-loss insurance).

Risk Adjustment — A statistical method of paying managed care organizations different capitated payments based on the composition and relative healthiness of their beneficiaries. This procedure would generally compensate providers of HIV services with a higher capitated payment than providers of other (often less costly) health care services.

Risk Corridor — A financial arrangement between a payer of health care services, such as a state Medicaid agency, and a provider, such as a managed care organization that spreads the risk for providing health care services. Risk corridors protect the provider from excessive care costs for individual beneficiaries by instituting stop-loss protections and they protect the payer by limiting the profits that the provider may earn.

Risk Sharing — A financial arrangement between health care providers, managed care organizations and another entity such as a state Medicaid program in order to spread the risk of providing health care services. This type of arrangement is often employed to protect providers and managed care organizations serving chronically ill individuals (such as people living with HIV) from financial insolvency.

Specialty Gatekeeper — A health care provider within a managed care organization with expertise in HIV care (or a specific area of medicine) who makes decisions regarding referrals to other providers and when it is necessary to provide specific health care services. For persons living with HIV, it is particularly important to have the designated care coordinator experienced and knowledgeable in treating HIV.

Staff Model HMO — A type of managed care organization that hires its own doctors as salaried employees, and generally owns its own clinics and health care facilities.

Standing Referral — A referral to a specialist provider that covers routine visits to that provider. It is a common practice to permit the gatekeeper to make referrals for only a limited number of visits (often 3 or fewer). In cases where the medical condition requires regular visits to a specialist, this type of referral eliminates the need to return to the gatekeeper each time the initial referral expires.

Stop-Loss Insurance — A type of insurance that managed care organizations purchase to protect against excessive costs associated with a few high-cost beneficiaries.

Utilization Review — A management technique designed to reduce unnecessary health care costs or to ensure that the least costly care option is provided. Utilization review can include: pre-certification which requires the approval of a managed care organization before a specific health care service is provided; case management which involves designating a nurse or other employee to monitor and coordinate the care that a patient receives; or imposing second opinion requirements in which a second specialist must agree that a specific health care procedure is necessary before the managed care organization will agree to approve the expense. Various utilization review techniques can take place at different stages in the delivery process (i.e. before, during, and after a service is provided).

Waiver — Approval that the Health Care Financing Administration (HCFA, the federal agency that administers the Medicaid program) may grant to state Medicaid programs to exempt them from specific aspects of Title XIX, the federal Medicaid law. Most federal waivers involve loss of freedom of choice regarding which providers beneficiaries may use, exemption from requirements that all Medicaid programs be operated throughout an entire state, or exemption from requirements that any benefit must be available to all classes of beneficiaries (which enables states to experiment with programs only available to special populations).

The federal government has only granted waivers in cases where the public has had an opportunity to provide input, and where the waivers are designed to protect both access to and quality of care.

Medicaid waivers have been used to allow states to mandatorily enroll Medicaid beneficiaries into managed care. Some of these waivers have used mandatory enrollment into managed care as a means of expanding Medicaid coverage to uninsured groups of individuals.

Resources

NAPWA serves as the voice of all people living with HIV. NAPWA conducts policy analysis on Medicaid, Medicare, the Ryan White CARE Act, and the private health insurance market and also operates an information and referral program for individuals seeking information on health care and other services available in their own community. The following organizations are also engaged in various projects and activities related to Medicaid managed care:

Henry J. Kaiser Family Foundation
2400 Sand Hill Road
Menlo Park, CA 94025
PHONE: (415)854-9400
FAX: (415)854-4800
WEB SITE: http://www.kff.org
PUBLICATION REQUEST LINE: (800)656-4KFF
FAX BACK: (888)KFF-AIDS

The Kaiser Family Foundation, based in Menlo Park, California, is an independent national health care philanthropy and is not associated with Kaiser Permanente or Kaiser Industries. The Foundation's work is focused on four main areas: health policy, reproductive health, HIV, and health and development in South Africa.

AIDS Action Council
1875 Connecticut Avenue, NW, Suite 700
Washington, DC 20009
PHONE: (202)986-1300
FAX: (202)986-1345
E-MAIL: HN3384@handsnet.org

AIDS Action provides federal-level advocacy and policy analysis on Medicaid, Medicare, managed care, and other health care access issues for people living with HIV and AIDS.

AIDS Housing of Washington
2025 First Avenue, Suite 420
Seattle, WA 98121
PHONE: (206)448-5242
FAX: (206)441-9485
E-MAIL: HN3836@handsnet.org

AIDS Housing of Washington offers technical assistance to AIDS housing and service providers on housing operations and planning issues, licensing, and developing partnerships between housing and service providers.

AIDS Policy Center for Children, Youth and Families
918 16th Street, NW
Washington, DC 20006
PHONE: (202)785-3564
FAX: (202)785-3578
E-MAIL: APCCYF@aol.com

The AIDS Policy Center provides technical assistance on the Medicaid managed care process with special emphasis on issues affecting children with HIV.

American Psychological Association
Public Policy Office
750 First Street, NE
Washington, DC 20002-4242
PHONE: (202)336-6068
FAX: (202)336-6063
E-MAIL: igp.apa@email.apa.org

The American Psychological Association provides federal advocacy and policy analysis on Medicaid, Medicare, health insurance reform, and other health care access issues affecting people living with HIV. Special emphasis is placed on advocating for the mental health and substance abuse treatment needs of vulnerable populations.

Center on Budget and Policy Priorities
820 First Street, NE, Suite 810
Washington, DC 20002
PHONE: (202)408-1080
FAX: (202)408-1056
E-MAIL: center@center.cbpp.org/
HN0026@handsnet.org

The Center on Budget and Policy Priorities provides research and policy analysis on a broad range of budget and policy issues, with an emphasis on those issues affecting low- and moderate-income Americans. The Center has done extensive analysis of the fiscal and policy impact of various proposals for Medicaid reform.

Families USA
1334 G Street, NW
Washington, DC 20005
PHONE: (202)628-3030
FAX: (202)347-2417
E-MAIL: info@familiesusa.org

Families USA provides technical assistance, policy support, media training and organizing support to state-level Medicaid managed care efforts.

Gay Men's Health Crisis
129 W. 20th Street
New York, NY 10011
PHONE: (212)337-3342
FAX: (212)337-1220
E-MAIL: susand@gmhc.org

Gay Men's Health Crisis produces waiver analysis documents, briefing papers on managed care and people with AIDS, consumer education on managed care for people with AIDS, and has helped to draft a Managed Care Bill of Rights.

Health Care Financing Administration (HCFA)
7500 Security Boulevard
Baltimore, MD 21244-1850
PHONE: (410)786-3000
E-MAIL: Question@hcfa.gov

HCFA is the federal agency that administers the Medicaid program.

Health Resources and Services Administration (HRSA)
Center on Managed Care
5600 Fishers Lane
Rockville, MD 20857
PHONE: (301)443-0863
FAX: (301)443-1551

HRSA's Center on Managed Care works to ensure that HRSA's programs and the vulnerable populations they serve are active and knowledgeable participants in managed care systems. The Center offers a coordinated program of technical assistance, training, evaluation and interagency collaboration. HRSA HIV/AIDS program staff also review and provide comments on Medicaid waiver applications.

Housing Works (Albany Office)
247 Lark Street, First Floor
Albany, NY 12165
PHONE: (518)449-4207
FAX: (518)449-4219
E-MAIL: mkink@ix.netcom.com

Housing Works provides advocacy and policy analysis on Medicaid and managed care issues in New York City and New York State. Special emphasis is placed on articulating the health care needs of homeless and formerly homeless people with AIDS.

Medicaid Working Group/ Boston University School of Public Health
441 Stuart Street, Sixth Floor
Boston, MA 02116
PHONE: (617)437-1550
FAX: (617)437-0031
E-MAIL: tcarol@bu.edu

The Medicaid Working Group provides training, education and technical assistance to states, providers and consumers on managed care for people with disabilities. Technical assistance includes Medicaid contracting, rate-setting, benefits, provider networks, and quality standards.

National Academy for State Health Policy
50 Monument Square, Suite 502
Portland, ME 04101
PHONE: (207)874-6524
FAX: (207)874-6527

NASHP serves as a technical resource center for states. It acts as a clearinghouse for best practices, as well as providing direct technical assistance to state policymakers.

National Health Law Program
2369 South La Cienega Boulevard
Los Angeles, CA 90034
PHONE: (310)204--6010
FAX: (210)204-0891
E-MAIL: nhelp@healthlaw.org

NHeLP is a national public interest law firm with extensive expertise related to Medicaid and managed care. NHeLP has produced managed care consumer education materials and has anaylzed state Medicaid waivers.

National Minority AIDS Council
1931 13th Street, NW
Washington, DC 20009
PHONE: (202)483-6622
FAX: (202)483-1135
E-MAIL: NMAC1@aol.com

NMAC provides policy analysis and advocacy on Medicaid and managed care and its impact on people with HIV.

Northwest AIDS Foundation
127 Broadway East, Suite 200
Seattle, WA 98102-5786
PHONE: (206)329-6923
FAX: (206)325-6923
E-MAIL: STEVEJ@sisna.com

NWAF provides state and federal advocacy efforts on Medicaid and managed care, as well as other health care concerns of individuals living with HIV/AIDS.

Project Inform
1945 Market Street, Suite 220
San Francisco, CA 94103-1012
PHONE: (415)558-8669
FAX: (415)558-0684
E-MAIL: Pinform@hooked.net

Project Inform provides information to consumers and advocates for people living with HIV. Project Inform also advocates on issues related to Medicaid and managed care.

San Francisco AIDS Foundation
P. O. Box 426182
San Francisco, CA 94142-6182
PHONE: (415)487-3000
FAX: (415)487-3089

SFAF engages in San Francisco County-level advocacy on Medicaid and private-sector managed care, as well as advocating on the state and federal levels.

Texas AIDS Network
P.O. Box 2395
Austin, TX 78768
PHONE: (512)447-8887
FAX: (512)447-1115
E-MAIL: tan@global.org

Texas AIDS Network advocates on behalf of people living with HIV in Texas. This includes working at the state and federal level on issues related to Medicaid and managed care.

BOARD OF DIRECTORS

the
National
Association
of People
with
AIDS

Chair Jim Graham
Whitman-Walker Clinic
Washington, DC

Vice Chair Roger Gooden
Missouri Prevention/Care Collaboration Task Force
Kansas City, Missouri

Treasurer Thomas S. Berg
United Way of Cascade County
Great Falls, Montana

Secretary Belynda A. Dunn
AIDS Action Committee of Massachusetts
Boston, Massachusetts

Val Biäs
National Hemophilia Foundation
Washington, DC

Bartholomew T. Casimir
American College of Chinese Medicine
San Francisco, California

Pat Christen
San Francisco AIDS Foundation
San Francisco, California

William J. Gunn
Hill & Knowlton
Atlanta, Georgia

David S. Landay, J.D.
National Viator Representatives
New York, New York

Rex J. Sandborg
Cook County HIV Primary Care Center
Chicago, Illinois

Valerie P. Setlow, Ph.D.
Institute of Medicine/National Academy of Sciences
Washington, DC

Paul Wisotzky
Harder + Company Community Research (former)
San Francisco, California

A. Cornelius Baker, Executive Director

Jeffrey S. Crowley, M.P.H., Project Director

FAMILY VOICES

A national grassroots network of families and friends speaking on behalf of children with special health care needs.

Report on the Family Voices Managed Care Survey in Atlanta, Denver, Des Moines and Seattle

Background

Family Voices is a national grassroots network of more than 12,000 families and friends concerned about children with special health care needs, i.e. children who have a greater need for health care services than most children. Our members are a diverse group, representing children with a wide variety of health conditions, from many cultures and backgrounds living in rural, suburban and urban communities across the United States. Because their children depend so much on health care to lead safe and happy lives, our families have extensive experience with what works and what doesn't in health care for children with special needs. Our members are active at all levels of health care systems, serving in many capacities from volunteers to paid staff in hospitals, health care plans, state Title V Children with Special Health Care Needs Programs and state Medicaid Agencies. Many members serve on local, state, regional and national committees working on managed care and health care systems changes.

Family Voices believes that a strong consumer voice will promote services that meet consumer needs, facilitate access to appropriate care for vulnerable children, and overall, lead to better quality of care. While there has been rapid movement of many families into managed care in both public and private sectors, there is little information on how these managed care plans meet the special needs of children with disabilities. We believe, in principle, that managed care has the potential for strengthening and coordinating essential services for children with disabilities. This will only be achieved, however, by enabling the families who face the day-to day demands of navigating complex systems of care for their children to give direction and feedback to the systems that serve their children and to participate in substantive ways in program and policy development as managed care products are designed and implemented.

To this end, in October of 1995, Family Voices began a one-year project, funded through the Annie E. Casey Foundation, that included surveying members of families with children with special health needs in four selected cities: Atlanta, Denver, Des Moines, and Seattle about their experiences with their health plan.

Survey Design

The survey was designed as a tool to give feedback to the health care system from families of children with special health needs and to inform program and policy makers about families' perspectives in this time of rapid change. We wanted to gather information from families with children in both managed care and non managed care plans in order to establish a baseline of information about children with special health needs and how families view these children's health coverage.

In the Spring of 1995 Family Voices developed and distributed a draft questionnaire at an annual national training conference. This pilot asked questions which reflected the numerous concerns Family Voices staff were hearing from families across the country about their children's health care coverage. The survey was completed by 43 Family Voices State Coordinators, recognized family leaders. The family responses provided interesting information from a small number of families about how health plans were addressing the needs of children with special health needs. Insight gained from that pilot helped to shape the questionnaire used in the Casey study.

Family Voices worked in cooperation with New England Serve to develop a joint questionnaire to ~~be~~ used by both groups. This second questionnaire was designed to gather information from families regarding their child with special needs' use of health services and their satisfaction with 52 specific health services and delivery characteristics of their child's health plan. Children with special needs were broadly defined for this study as children who had health needs greater than those of normal children of a similar age. Questions were asked about their limitations of physical function, activities of daily living or social role in comparison to their age peers, as ~~well as~~ their needs for special health services. Demographic information including race, socio-economic status and education was included. A telephone number was provided for respondents to call in case they had any questions.

Distribution of the Questionnaire

Coordinators in each of the four cities distributed the questionnaire to families in a variety of ways. The majority of questionnaires were distributed by mail through family mailing lists and through cooperating programs, although other methods included leaving questionnaires in specialty and hospital clinics with drop boxes for questionnaire return, and distributing questionnaires at family meetings, in community meetings, and in person. In a few cases, questionnaires were completed through a telephone interview. It is difficult to report the return rate, since the methods of distribution varied widely and we are uncertain how many surveys were distributed.

A total of 330 surveys were returned by the time of data analysis, of which 323 were determined to be from families with children fitting our description of children with special health care needs; 104 from Seattle, 117 from Atlanta, 52 from Denver and 50 from Des Moines. The sample of families was not selected in a controlled manner.

The Results of the Survey

Who were the Families Responding?

The Family Voices surveys reached a diverse group of families, as shown in Table 1, with variations by site roughly representative of the composition of the different cities. Household incomes reported were from every category, with 36% of respondents overall indicating incomes under $30,000. One quarter of respondents reported having a high school education or less; another 21% reported "some college." A small percentage of respondents responded that their primary language was not English.

The highest percentage of families responding had health coverage for their child through the parents' employment (63%). Twenty eight percent of the families responding received coverage for their child through Medicaid and another 3.8% reported coverage through other state supported plans. In more than a quarter of the families responding, the child qualified for SSI. Families were asked whether the health insurance they had for their child was either a Preferred Provider Organization, a Health Maintenance Organization, the child was not in a managed care plan, or other. The majority of the families responding had children covered through some form of managed care plan (65%), while 15% reported that their child was not in a managed care plan and 19% did not classify their child's plan but reported "other."

What were the Health Needs of the Children in the Survey?

In every city, the majority of respondents reported having children with four or more specific special health needs, suggesting that the responding families had children with significant need for services. Among the 323 respondent questionnaires analyzed, most families reported that their child had limitations in function (75.2%) as well as needs for a variety of special health services, with the most commonly reported need (82%) being therapeutic services (see Table 4). Although the respondents reported that their children needed a large number of services, these children were also most often treated outside of hospital settings as can be seen in Table 3. Within the past 12 months, while a majority had seen their primary care provider more than 6 times and 42.3% had seen a pediatric specialist more than 5 times, 49% had not been seen in an emergency room, and 56% had not had a hospital stay. Respondents' children with special needs were from every age range, although more were 3 and under, and fewer were over age 13.

What did these Families Report about Health Care for their Child?

Family satisfaction with 27 health services and 25 aspects of service delivery are reported in a variety of ways in Tables 6-16. A broad view of the findings are discussed below. Please refer to the tables for more complete information.

1. Overall, services used by the most respondents received the highest satisfaction ratings.[1] (Tables 7 & 8) For example:

- Services that over 70 % of respondents needed and used and with which more than 50 % of respondents reported being "very satisfied" included: *appropriate routine well child care, a primary care provider with knowledge of my child's special needs, prescription medications*, and *laboratory services*
- "Delivery characteristics" that over 70% of respondents used and with which more than 50% were "very satisfied" included: *having time with my child's*

---

[1] The percent of use of service was derived by dividing the total respondent population into the number using the service ("N") for each use category

provider to ask questions, family inclusion in decision making and planning and *waiting time to schedule appointments for primary care.*

- *Speech therapy* was the only service that over 70% of respondents indicated needing/using but for which more than 40% of respondents indicated unmet needs, i.e."not satisfied" or "needed but not available."

2. Overall, services that fewer respondents reported needing received lower satisfaction ratings

- *Home nursing, personal care attendants, hospice services* and *counseling for my child* were used by fewer than 30% of all respondents and over 40% of these respondents indicated unmet needs, i.e. "not satisfied" or "needed but not available". None of the services for which fewer than 30% of all respondents indicated a need were rated highly by respondents.
- Mental health services including *counseling for family members, family support groups*, and *out-patient diagnostic services* that a moderate number of respondents (30%-69%) reported needing and using, had over 40% of respondents indicating unmet need, i.e. "not satisfied" or "needed not available". These mental health services received the lowest overall rating among the direct services.

3. Delivery of service areas that many respondents were dissatisfied with may lend themselves to low cost solutions (Tables 7 & 9) For example:

- Over 40% of all respondents were dissatisfied with *appeals or grievance procedures*. This points to a need for more straightforward information on appeals and grievances to be given to every enrollee in every plan.
- Over 40% of respondents were dissatisfied with *information about current research that might help my child.* This probably reflects a desire for more information. Plans could help families access medical information, now readily available from many sources including the internet.
- Over 40 % of respondents were dissatisfied with *helping the school understand my child's special needs.* Knowing that this is an issue, plans might

improve family satisfaction by working with families to develop low cost mechanisms for effective communication with school systems.

- Over 40 % of respondents were dissatisfied with *transition from adolescent to adult services*. Proactive identification of adult providers, and planning and coordination for these transitions within plans could address this issue.
- Over 40% of respondents were dissatisfied with the *flexibility to use cost effective alternative services, equipment or providers*. Case management programs in traditional insurance plans that have allowed cost effective alternatives to be approved in specific cases have been in effect for a number of years. These models could be adapted to meet the needs of a wide range of children with special needs in all kinds of plans.
- Over 40 % of respondents were dissatisfied with *waiting time to approve special services or equipment*. A first approach to improving this situation would be for plans to give families clear information on the expected waiting times for such approvals, and how they might check on the status of their request. Eliminating "pro forma" procedures for reviewing cases when an ongoing need has been documented, and development of a "long term care plan" in which pre-approval was given for longer time frames could prove more cost effective and efficient for the plan and more satisfactory for the family.

4. Families with children not in managed care were considerably more satisfied than those in managed care with services and service delivery areas that are of most importance to children with special needs (Table 10) For example:

- Families were twice as likely to be highly satisfied in non-managed care plans as in managed care plans (% highly satisfied in HMO, PPO, not in managed care) with services such as *durable medical equipment*, (35%,33%,71%) *adaptive equipment* (23%, 20%, 60%), *disposable medical supplies* (42%, 38%, 86%), *nutritional products* (29%, 18%, 60%), *home nursing services* 27%, 35%, 57%), *personal care attendant services* (31%, 20%, 67%), *emergency room services* (41%, 48%, 79%)

- Families were twice as likely to be highly satisfied in non-managed care plans as in managed care plans with aspects of service delivery of greatest importance to children with special needs (% highly satisfied in HMO, PPO, not in managed care) such as *access to a case manager or care coordinator* (25%, 29%, 59%), *access to second opinions* (27%, 39%, 59%), *appeals or grievance procedures* (12%, 15%, 42%), and *flexibility to use cost-effective providers* (21%, 24%, 41%).
- The smallest variation in percent of families reporting high satisfaction is seen in *appropriate well child care* (HMO, PPO, not in managed care; 69%, 66%, 60%).

5. Responses from families not in managed care compared to those in two categories of managed care plans show a pattern of decreasing satisfaction with both services and delivery as choice is restricted (Tables 6,11, 12 &13) For example:

- In *overall evaluation of child's health plan,* 63% of families not in managed care plans gave their child's plan the highest ratings, as compared to 58% of families in PPOs and 46% of families in HMOs.(Table 6).
- In *child's health plan covers costs to meet child's needs,* 53% of families not in managed care said that their child's health plan covers costs to meet the child's needs, as compared to 49% of families in PPOs and 41% of families in HMOs.(Table 6)
- Respondents in managed care plans were less likely to be "very satisfied" than those not in a managed care plan when rating specific services. In 21 of the 27 health services categories, families not in managed care plans were more highly satisfied than those in PPOs and HMOs. (Table 10)
- Families not in managed care gave the highest satisfaction ratings in 21 of the 25 categories of service delivery, while those in HMOs and PPOs gave the highest ratings in only two categories each. (Table 10)
- ~~The~~ most unmet needs (represented by the combination of the "not satisfied" and "needed/not available" responses) were reported by respondents in HMOs (in 16 of the 27 direct service categories) while those in PPOs indicated the

most unmet needs in 3 categories and those in not in managed care in 8 categories. (Table 11)

- Respondents in HMOs had the lowest satisfaction ratings in the most categories of service delivery. In service delivery items those in HMOs reported lowest satisfaction in 13 out of 25 categories, while those in PPOs reported lowest satisfaction in 8 categories, and those not in managed care in 4 categories. (Table 12)

Implications

The information gathered in these surveys indicates progress toward providing family-centered care for children with special health care needs, evidenced in high levels of family satisfaction that their children are receiving good primary care. Over half of all respondents in both managed care and non-managed care plans also indicated high satisfaction that their child is receiving care from appropriate pediatric specialty providers. Families in both non-managed care and managed care health plans also reported relatively high satisfaction with most coverage of traditional, hospital based and "well care" services for children with special needs. (An exception to this pattern was in emergency-room services with which 41% of families in HMOs and 48% of families in PPOs compared to 79% of families in non-managed care plans were highly satisfied. Table 10).

Families in all health plans, but particularly those in managed care plans, however, indicated that they are not as satisfied with their child's coverage for many specialized services needed by children with special needs including physical, occupational and speech therapies, durable medical and adaptive equipment and home care including supplies. These findings are consistent with those of our earlier Family Voices survey, although the spread of variation in satisfaction reported was greater in this survey. In the area of service delivery, there were strong differences in family satisfaction between families in non managed care and managed care plans in accessing care coordinators, second opinions, appeals and flexibility to use cost-effective providers, key services to families of children with special needs. Since families in non-managed care plans reported significantly higher satisfaction in all these areas, aspects of non-managed care plans should be examined carefully to explain why they are more satisfactory to families. As greater numbers of children with special health care needs are enrolled in managed care plans, it will become increasingly important to understand how the desirable characteristics of non-managed care plans can be adapted by managed care organizations to meet the special needs of these vulnerable children.

There is also a need for all plans to direct attention to some particular services, needed by the smallest percentage of children, such as hospice, home care and personal care. It was impossible to distinguish whether type of health plan affected the family satisfaction with these services since the numbers of responses in these categories were too few in this study. This finding identifies a key area to track, however, which is a plan's familiarity with effective and efficient pediatric models of such services for children. All plans also need to improve mental health services for families including counseling for the child, counseling for other family members, diagnostic out-patient services, family support groups and in-patient services, with well over half of families in all kinds of plans identifying most of these services as not satisfactory or needed but not available. Counseling for the child was the area of greatest "unmet need" (89% of families not in managed care, 60% HMO, 54% PPO, Table 11) Clearly mental health services need further investigation and attention.

Next Steps

The family experiences collected in this survey offer valuable information to families, managed care organizations, Medicaid agencies and other public and private policymakers, particularly in the current climate of rapid change in our health care systems. This information can help improve the way the current system is working as well as identify issues for further examination and discussion. Families must continue to be directly involved in efforts to collect and report such information. Families of children with special needs are willing and able to provide a wealth of information which can be helpful in focusing efforts of managed care organizations on areas of need. Families also have a number of creative solutions to problems and are ready and willing to act as partners with program and policy makers.

Family Voices will use lessons learned from this activity to guide our future information gathering approaches. Families filling out this questionnaire were eager to offer their comments. They provided helpful information about ways to make the questionnaire more family friendly. As we continue to collect information from families, Family Voices will seek help from research experts to assist in survey design, sampling strategies and data analysis.

We thank the families who filled out this questionnaire, our Casey site leaders, research consultants, Family Voices staff and all our partners, and most especially the Annie E. Casey Foundation through whose funding this effort was possible, for their collaboration in this initial survey process. Family Voices believes that families are the heart of our nation's health care systems and the experts on their children. We think this modest survey proves our point.

This data has been collected and analyzed through a project funded by the Annie E. Casey Foundation *June 1997*

For further information, please contact:

Nora Wells
Family Voices
Federation for Children with Special Needs
95 Berkeley St., Suite 104
Boston, MA 02116
(617) 482-7363 ext. 123

Table 1
Family Voices Survey on Managed Care
Family and Child Characteristics of Respondents
(N=323)

	Total N=323		Seattle, WA n=104		Atlanta, GA n=117		Denver, CO n=52		DesMoines, IA n=50	
Family Characteristic	n	%	n	%	n	%	n	%	n	%
Child's Racial/Ethnic Background										
White	233	76.6	84	82.4	67	64.4	37	75.5	45	91.8
African-American	34	11.2	6	5.9	25	24.0	1	2.0	2	4.1
Hispanic	12	4.0	2	2.0	5	4.8	5	10.2	0	0.0
Other	25	8.2	10	9.8	7	6.7	6	12.2	2	4.1
Parent's Primary Language										
English	295	96.4	100	97.1	100	95.2	46	93.9	49	100
Other	11	3.6	3	2.9	5	4.8	3	6.1	0	0.0
Parent's Household Income										
Less than $10,000	34	11.9	14	14.6	14	13.9	3	7.0	3	6.4
$10,000 - $19,999	35	12.2	10	10.4	16	15.8	6	14.0	3	6.4
$20,0000 -$29,999	34	11.9	6	6.3	17	16.8	5	11.6	6	12.8
$30,000 - $39,999	47	16.4	16	16.7	13	12.9	8	18.6	10	21.3
$40,0000 -$60,000	67	23.3	27	28.1	15	14.9	11	25.6	14	29.8
More than $60,000	70	24.4	23	24.0	26	25.7	10	23.3	11	23.4
Parent's Education										
Less than High School	12	3.9	4	3.9	3	2.9	2	4.2	3	6.3
High School or Technical School Grad	69	22.6	15	14.4	32	30.5	11	22.9	11	22.9
Some College	65	21.3	25	24.0	15	14.3	12	25.0	13	27.1
College Graduate	159	52.1	60	57.7	55	52.4	23	47.9	21	43.8
Continuous Telephone Service for the Last 6 Months	281	93.4	99	97.1	95	93.1	41	85.4	46	93.9
Difficulty Getting Transportation for Child's Medical Appointments										
Yes	32	10.7	7	6.9	12	12.0	8	16.7	5	10.2
No	267	89.3	95	93.1	88	88.0	40	83.3	44	89.8

Table 2
Family Voices Survey on Managed Care
Family Responses Concerning Child Needs and Health Plan Coverage
(N=323)

Child Needs and Health Plan Coverage	Total N=323		Seattle, WA n=104		Atlanta, GA n=117		Denver, CO n=52		DesMoines, IA n=50	
	n	%	n	%	n	%	n	%	n	%
Number of Special Needs										
1	30	9.5	7	6.9	19	16.7	1	2.0	3	6.1
2	50	15.8	14	13.7	24	21.1	6	11.8	6	12.2
3	43	13.6	13	12.7	16	14.0	4	7.8	10	20.4
4	39	12.3	13	12.7	10	8.8	9	17.7	7	14.3
5 or more	154	48.7	55	53.9	45	39.5	31	60.8	23	46.9
Age of Child										
0-3 years	105	32.9	33	32.3	41	35.6	12	23.1	19	38.0
4-6 years	75	23.5	26	25.5	30	26.1	13	25.0	6	12.0
7-12 years	84	26.3	30	29.4	29	25.2	15	28.8	10	20.0
13-18 years	44	13.8	12	11.7	12	10.4	10	19.2	10	20.0
19 and older	10	3.1	1	1.0	2	1.7	2	3.8	5	10.0
Child Receives Supplemental Security Income (SSI)	83	27.5	25	24.8	37	35.2	12	25.5	9	18.4
Description of Child's Health Plan**										
HMO	84	33.2	29	33.0	20	22.5	15	40.5	20	51.3
PPO	81	32.0	34	38.6	27	30.3	15	40.5	5	12.8
Other	49	19.4	14	15.9	27	30.3	1	2.7	7	18.0
Not in a Managed Care Plan	39	15.4	11	12.5	15	16.9	6	16.2	7	18.0
Child's Health Insurance										
Parent's Employer	200	63.3	67	65.7	61	54.0	34	65.4	38	77.5
Non-group Policy	8	2.5	3	2.9	5	4.4	0	0.0	0	0.0
Medicaid	87	27.5	21	20.6	43	38.1	16	30.8	7	14.2
CHAMPUS	1	0.3	1	1.0	0	0.0	0	0.0	0	0.0
State-supported Special Plan	12	3.8	6	5.8	3	2.7	0	0.0	3	6.1
Other	8	2.5	4	3.9	1	0.9	2	3.9	1	2.0

** *Respondents who indicated that their child is covered by more than one type of health plan were not included in the analysis for this item.*

Table 2 (continued)
Family Voices Survey on Managed Care
Family Responses Concerning Child Needs and Health Plan Coverage

Child Needs and Health Plan Coverage	Total N=323		Seattle, WA n=104		Atlanta, GA n=117		Denver, CO n=52		DesMoines, IA n=50	
	n	%	n	%	n	%	n	%	n	%
Child's Length of Membership in Health Plan										
Less than 1 year	68	23.8	22	22.7	32	34.0	9	18.8	5	10.6
1-2 years	86	30.1	33	34.0	22	23.4	14	29.2	17	36.2
3-5 years	77	26.9	19	19.6	28	29.8	14	29.2	16	34.0
More than 5 years	55	19.2	23	23.7	12	12.8	11	22.9	9	19.1
Respondent Has Same Health Plan as Child										
Yes	225	71.4	83	81.4	73	64.6	31	60.8	38	77.6
No	90	28.6	19	18.6	40	35.4	20	39.2	11	22.5
Parent Requested Special Exception to Policy from Child's Plan										
Yes	69	23.2	29	29.0	20	19.8	13	27.1	7	14.3
No	229	76.9	71	71.0	81	80.2	35	72.9	42	85.7

Table 3
Family Voices Survey on Managed Care
Family Reports of Child's Use of Health Care System
(N=323)

	Total N=323		Seattle, WA n=104		Atlanta, GA n=117		Denver, CO n=52		DesMoines, IA n=50	
Child Use of Health Care System	n	%	n	%	n	%	n	%	n	%
Child Seen as Outpatient by PC Provider in Past 12 Months:										
0 times	7	2.2	2	1.9	3	2.7	2	3.9	0	0.0
1-2 times	51	16.2	16	15.4	16	14.6	7	13.7	12	24.0
3-5 times	99	31.4	33	31.7	35	31.8	13	25.5	18	36.0
6-8 times	52	16.5	16	15.4	20	18.2	10	19.6	6	12.0
More than 8 times	106	33.7	37	35.6	36	32.7	19	37.3	14	28.0
Child Seen as Outpatient by Specialist in Past 12 Months:										
0 times	29	9.2	9	8.7	14	12.5	4	7.7	2	4.0
1-2 times	76	24.0	25	24.3	17	15.2	17	32.7	17	34.0
3-5 times	78	24.6	26	25.2	34	30.4	5	9.6	13	26.0
6-8 times	49	15.5	16	15.5	16	14.3	11	21.2	6	12.0
More than 8 times	85	26.8	27	26.2	31	27.7	15	28.9	12	24.0
Child Hospitalized in Past 12 Months:										
0 times	178	56.0	58	56.3	64	56.1	27	51.9	29	59.2
1-2 times	106	33.3	31	30.1	39	34.2	20	38.5	16	32.7
3-5 times	24	7.6	10	9.7	11	9.7	1	1.9	2	4.1
6-8 times	4	1.3	2	1.9	0	0.0	1	1.9	1	2.0
More than 8 times	6	1.9	2	1.9	0	0.0	3	5.8	1	2.0
Child's Longest Hospital Stay in Past 12 Months:										
0 days	170	54.3	59	57.8	56	50.9	26	50.0	29	59.2
1-2 days	41	13.1	14	13.7	14	12.7	8	15.4	5	10.2
3-5 days	52	16.6	15	14.7	19	17.3	9	17.3	9	18.4
6-8 days	14	4.5	5	4.9	4	3.6	2	3.9	3	6.1
9-14 days	16	5.1	3	2.9	9	8.2	1	1.9	3	6.1
More than 14 days	20	6.4	6	5.9	8	7.3	6	11.5	0	0.0
Child Treated in Emergency Room in Past 12 Months										
0 times	154	49.0	54	51.9	46	41.8	26	51.0	28	57.1
1-3 times	119	37.9	35	33.7	44	40.0	20	39.2	20	40.8
4-10 times	37	11.8	12	11.5	19	17.3	5	9.8	1	2.0
11-20 times	2	.6	2	1.9	0	0.0	0	0.0	0	0.0
More than 20 times	2	.6	1	1.0	1	.9	0	0.0	0	0.0

Table 4
Family Voices Survey on Managed Care
Family Respondents' Description of Special Health Needs of Children
(N=323)

Special Health Care Need	Total		Washington		Georgia		Colorado		Iowa	
	N	%	n	%	n	%	n	%	n	%
Limitation of Physical Functioning (ADL or social role)	243	75.2	89	85.6	77	65.8	44	84.6	33	66.0
Need for Specialized Service										
Therapeutic Services (physical/occupational/speech therapy)	266	82.3	93	89.4	90	76.9	44	84.6	39	78.0
Home Health Care	60	18.6	21	20.2	14	12.0	16	30.8	9	18.0
Use of Durable Medical Equipment or Assistive Devices	125	38.7	40	38.5	40	34.2	26	50.0	19	38.0
Medications	158	48.9	53	51.0	55	47.0	23	44.2	27	54.0
Special Diets	99	30.7	37	35.6	28	23.9	21	40.4	13	26.0
Medical Technology	77	23.8	24	23.1	21	18.0	22	42.3	10	20.0
Personal Care Assistance	106	32.8	44	42.3	25	21.4	21	40.4	16	32.0
Multidisciplinary Assessments	134	41.5	46	44.2	36	30.8	31	59.6	21	42.0
Specialized Mental Health Interventions	45	13.9	16	15.4	13	11.1	7	13.5	9	18.0
Care Coordination Among Multiple Providers	131	40.6	39	37.5	39	33.3	32	61.5	21	42.0
Need for Enhanced Medical Care above Usual for Child's Age	135	41.8	51	49.0	33	28.2	29	55.8	22	44.0

Table 5
Family Voices Survey on Managed Care
Family Responses on Overall Satisfaction and Costs
(N=323)

Child Needs and Health Plan Coverage	Total N=323		Seattle, WA n=104		Atlanta, GA n=117		Denver, CO n=52		DesMoines, IA n=50	
	n	%	n	%	n	%	n	%	n	%
Overall Evaluation of Child's Health Plan										
Appropriate, quality services	161	53.7	53	53.0	68	65.4	17	35.4	23	47.9
Moderately appropriate, quality services	89	29.7	31	31.0	22	21.2	20	41.7	16	33.3
Inadequate services	50	16.7	16	16.0	14	13.5	11	22.9	9	18.8
Child's Health Plan Covers Costs to Meet Child's Needs										
Yes	141	46.7	45	44.6	56	52.8	22	45.8	18	38.3
Somewhat	129	42.7	50	49.5	40	37.7	18	37.5	21	44.7
No	32	10.6	6	5.9	10	9.4	8	16.7	8	17.0

Table 6
Family Voices Survey on Managed Care
Family Responses on Overall Satisfaction and Costs by Type of Health Plan
(N=193)*

Child Needs and Health Plan Coverage	HMO n=78		PPO n=80		No Managed Care n=35	
	n	%	n	%	n	%
Overall Evaluation of Child's Health Plan						
Appropriate, quality services	36	46.2	46	57.5	22	62.9
Moderately appropriate, quality services	28	35.9	21	26.3	7	20.0
Inadequate services	14	18.0	13	16.3	6	17.1
Child's Health Plan Covers Costs to Meet Child's Needs						
Yes	32	41.0	39	48.8	19	52.8
Somewhat	36	46.2	35	43.8	11	30.6
No	10	12.8	6	7.5	6	16.7

* *Respondents who indicated that their child is covered by more than one type of health plan or by a health plan categorized as "Other" were not included in the analysis for this table.*

Table 7
Family Voices Survey on Managed Care
Family Responses on Individual Satisfaction Items
(N=323)

Satisfaction with Health Services	% Very Satisfied	% Somewhat Satisfied	% Not Satisfied	% Needed, Not Available
Medical and Specialty Services				
1. Appropriate routine, well-child care (n=280)	67.1	23.2	3.6	6.1
2. A primary care provider with knowledge of my child's special needs (n=291)	54.0	26.8	14.8	4.5
3. Appropriate pediatric specialty care providers (n=281)	59.8	28.1	10.0	2.1
4. Appropriate pediatric in-patient hospital services (n=208)	64.4	28.8	6.3	.5
5. Specialized dental care or orthodontic services (n=197)	40.6	24.9	12.7	21.8
6. Physical therapy services (n=222)	49.5	21.2	13.5	15.8
7. Occupational therapy services (n=212)	38.7	22.2	15.6	23.6
8. Speech therapy services (n=242)	38.4	19.4	16.5	25.6
9. Nutritional counseling (n=141)	39.7	17.0	20.6	22.7
10. Psychological testing (n=131)	29.0	27.5	25.2	18.3
11. X-ray and radiology services (n=212)	63.7	31.6	3.8	.9
12. Laboratory services (n=238)	61.8	31.9	4.6	1.7
13. Genetic counseling services (n=123)	50.4	24.4	15.4	9.8
14. Emergency room services (n=215)	54.0	37.2	7.9	.9
Mental Health Services				
1. Counseling for child (n=93)	24.7	15.1	32.3	28.0
2. Counseling for family members (n=148)	20.9	19.6	27.0	32.4
3. Family support groups (n=159)	16.4	25.8	18.9	39.0
4. Out-patient diagnostic services (n=90)	38.9	28.9	16.7	15.6
5. In-patient psychiatric care (n=42)	23.8	19.0	33.3	23.8
Other Health Services				
1. Prescription medications (n=285)	62.5	31.2	5.3	1.1
2. Durable medical equipment (n=152)	39.5	34.9	19.7	5.9
3. Adaptive equipment (n=160)	26.3	28.1	28.8	16.9
4. Disposable medical supplies (n=109)	45.0	26.6	15.6	12.8
5. Nutritional products or special diets (n=105)	36.2	18.1	18.1	27.6
6. Home nursing services (n=84)	32.1	27.4	19.0	21.4
7. Personal care attendant services (PCA) (n=72)	29.2	19.4	15.3	36.1
8. Hospice services (n=24)	29.2	20.8	29.2	20.8

Table 7 (continued)
Family Voices Survey on Managed Care
Family Responses on Individual Satisfaction Items
(N=323)

Satisfaction with Delivery of Care:	% Very Satisfied	% Somewhat Satisfied	% Not Satisfied
Communication and Coordination of Care			
1. Information about my child's medical needs (n=290)	40.3	40.7	19.0
2. Explanation of medical treatments (n=289)	47.4	41.5	11.1
3. Having time with my child's provider to ask questions (n=290)	54.5	34.5	11.0
4. Family inclusion in decision-making and planning (n=279)	57.0	32.3	10.8
5. Child's participation in decision-making and planning (n=186)	41.4	38.2	20.4
6. Communication between my child's primary care provider and specialty care providers (n=257)	34.2	34.6	31.1
7. Access to a case manager of care coordinator (n=219)	32.0	25.6	42.5
8. Helping the school understand my child's special health care needs (n=229)	19.2	33.2	47.6
9. Information re: current research that might help my child (n=250)	14.0	24.8	61.2
10. TDD services for hearing impaired (n=34)	29.4	23.5	47.1
11. Translator/interpreter services (n=23)	39.1	30.4	30.4
12. Respect for my culture, ethnic identity and religious beliefs (n=177)	62.7	26.6	10.7
Overall Ease of Service Delivery			
1. Telephone access to providers (n=283)	45.6	36.7	17.7
2. Access to second opinions (n=242)	39.9	34.3	26.4
3. Ability to schedule timely specialty care appointments/referrals (n=277)	41.9	36.8	21.3
4. Waiting time to approve special services/equipment (n=240)	27.1	32.9	40.0
5. Appeals or grievance procedures (n=136)	15.4	38.2	46.3
6. Coordination of multiple appointments or visits (n=227)	36.6	38.8	24.7
7. Required paperwork to access services (n=249)	32.5	36.1	31.3
8. Handicapped accessibility of physical facilities (n=144)	53.5	31.9	14.6
9. Transition from adolescent to adult services (n=56)	21.4	23.2	55.4
10. Waiting time to schedule appts for primary care (n=275)	53.8	35.3	10.9
11. Waiting time on day of appointment (n=287)	42.9	41.1	16.0
12. Info on what services are covered by child's plan (n=286)	31.8	36.7	31.5
13. Flexibility to use cost-effective alternative services, equipment or providers (n=230)	22.6	30.4	47.0

Table 8
Family Voices Survey on Managed Care
Family Satisfaction with Needed Services: Comparison of "Very Satisfied" Responses to "Not Satisfied" and "Needed/Not Available" Responses Combined
(N=323)

Satisfaction with Health Services (listed in ascending order of satisfaction)	% Very Satisfied	% Not Satisfied and Needed, Not Available
Medical, Mental Health and Specialty Services		
X-ray/radiology (n=212)	63.7%	4.7%
Laboratory services (n=238)	61.8%	6.3%
Prescription medications (n=285)	62.5%	6.3%
Appropriate pediatric in-patient hospital (n=208)	64.4%	6.7%
Emergency room services (n= 215)	54.0%	8.8%
Appropriate well child care (n=280)	67.1%	9.6%
Appropriate pediatric specialty care providers (n=281)	59.8%	12.1%
A primary care provider with knowledge of my child's special needs (n=291)	54.0%	19.2%
Genetic counseling/testing (n=123)	50.4%	25.2%
Durable medical equipment (n=152)	39.5%	25.7%
Disposable medical supplies (n=109)	45.0%	28.4%
Physical therapy (n=222)	49.5%	29.3%
Specialized dental/orthodontic services (n=200)	41.0%	34.0%
Occupational therapy(n=212)	38.7%	39.2%
Home nursing services (n=84)	32.1%	40.5%
Speech therapy (n=242)	38.4%	42.1%
Nutritional counseling (n=141)	39.7%	43.3%
Psychological testing (n=131)	29.0%	43.5%
Adaptive equipment (n=160)	26.3%	45.6%
Nutritional products(n=105)	36.2%	45.7%
Hospice services (n=24)	29.2%	50.0%
Personal care attendant services (n=72)	29.2%	51.4%
In-patient psychiatric care (n= 42)	23.8%	57.1%
Family support groups (n=159)	16.4%	57.9%
Counseling for family members (n=148)	20.9%	59.5%
Counseling for child (n=93)	24.7%	60.2%

Table 9
Family Voices Survey on Managed Care
Family Satisfaction with Delivery of Services: Comparison of "Very Satisfied" Responses to "Not Satisfied" Responses
(N=323)

Satisfaction with Delivery of Health Services (listed in ascending order of satisfaction)	% Very Satisfied	% Not Satisfied (Needed, Not Available not a response option)
Respect for my culture/Ethnic identity/ religious beliefs (n=177)	62.7%	10.7%
Family inclusion in decision making and planning (n=279)	57.0%	10.8%
Waiting time to schedule appts with primary care provider (n=275)	53.8%	10.9%
Time with my child's provider to ask questions (n=290)	54.5%	11.0%
Explanation of medical treatments (n=289)	47.4%	11.1%
Handicapped accessibility of facilities (n=144)	53.5%	14.6%
Waiting time on day of appt (n=287)	42.9%	16.0%
Telephone access to provider (n=283)	45.6%	17.7%
Information about my child's medical needs (n=290)	40.3%	19.0%
Child's participation in decision making (n=186)	41.4%	20.4%
Ability to schedule timely specialty appts. (n=277)	41.9%	21.3%
Coordination of multiple appts (n=227)	36.6%	24.7%
Access to second opinions(n=242)	39.3%	26.4%
Translator/interpreter services (n=23)	39.1%	30.4%
Communication between child's primary care provider and specialty providers (n=257)	34.2%	31.1%
Required paperwork to access services (n=249)	32.5%	31.3%
Info on what services are covered by child's plan (n=286)	31.8%	31.5%
Waiting time to approve special services/equipment (n=240)	27.1%	40.0%
Access to a case manager or care coordinator (n=219)	32.0%	42.5%
Appeals or grievance procedures (n=137)	15.3%	46.7%
Flexibility to use cost effective alternative services, equipment, providers (n=234)	23.0%	47.0%
TDD services for hearing impaired(n=34)	29.4%	47.1%
Helping the school understand my child's special health care needs (n=232)	19.8%	47.4%
Transition from adolescent to adult services (n=56)	21.4%	55.4%
Information re current research that might help my child (n=255)	15.3%	60.0%

Table 10
Family Voices Survey on Managed Care
High Satisfaction by Type of Health Plan
(N=204)*

Type of Health Service	Percent of Respondents within each Type of Health Plan Indicating "Very Satisfied"					
	HMO		PPO		Not in Managed Care	
Medical and Specialty Services	n	%	n	%	n	%
1. Appropriate routine, well-child care	52	69.3	51	66.2	18	60.0
2. A primary care provider with knowledge of my child's special needs	38	50.0	40	51.3	21	65.6
3. Appropriate pediatric specialty care providers	41	54.7	44	57.1	21	70.0
4. Appropriate pediatric in-patient hospital services	36	64.3	30	58.8	17	81.0
5. Specialized dental care or orthodontic services	14	27.5	23	42.6	10	55.6
6. Physical therapy services	20	39.2	30	51.7	14	51.9
7. Occupational therapy services	14	29.2	22	37.3	12	48.0
8. Speech therapy services	20	30.3	27	39.7	13	44.8
9. Nutritional counseling	11	31.4	16	40.0	8	53.3
10. Psychological testing	7	22.6	10	27.8	7	38.9
11. X-ray and radiology services	34	61.8	34	60.7	15	68.2
12. Laboratory services	35	55.6	40	64.5	19	67.9
13. Genetic counseling services	20	55.6	12	52.2	7	53.9
14. Emergency room services	24	40.7	26	48.2	19	79.2
Mental Health Services						
1. Counseling for child	4	16.0	8	33.3	1	11.1
2. Counseling for family members	4	9.3	13	35.1	2	18.2
3. Family support groups	4	9.5	11	25.6	2	18.2
4. Out-patient diagnostic services	6	30.0	9	40.9	4	50.0
5. In-patient psychiatric care	3	37.5	3	27.3	0	0.0
Other Health Services						
1. Prescription medications	45	59.2	43	57.3	22	73.3
2. Durable medical equipment	12	35.3	13	33.3	12	70.6
3. Adaptive equipment	8	22.9	9	19.6	9	60.0
4. Disposable medical supplies	11	42.3	11	37.9	6	85.7
5. Nutritional products or special diets	7	29.2	5	17.9	6	60.0
6. Home nursing services	6	27.3	7	35.0	4	57.1
7. Personal care attendant services (PCA)	5	31.3	4	20.0	4	66.7
8. Hospice services	3	50.0	1	14.3	2	100.0

* *N = the number of respondents who identified a given type of health plan for their child <u>and</u> indicated their child needed or used a particular service. Respondents who indicated that their child is covered by more than one type of health plan or by a health plan categorized as "Other" were not included in the analysis for this table.*

Table 10 (continued)
Family Voices Survey on Managed Care
High Satisfaction by Type of Health Plan
(N=204)*

Delivery of Health Service	Percent of Respondents within each Type of Health Plan Indicating "Very Satisfied"					
	HMO		PPO		Not in Managed Care	
Communication and Coordination of Care	n	%	n	%	n	%
1. Information about my child's medical needs	26	33.3	35	46.1	14	45.2
2. Explanation of medical treatments	29	37.2	45	57.7	19	63.3
3. Having time with my child's provider to ask questions	40	51.3	40	51.3	24	77.4
4. Family inclusion in decision-making and planning	37	51.4	53	69.7	23	76.7
5. Child's participation in decision-making and planning	18	33.3	25	46.3	14	70.0
6. Communication between my child's primary care provider and specialty care providers	19	26.7	19	27.5	16	59.3
7. Access to a case manager of care coordinator	14	25.0	16	29.1	13	59.1
8. Helping the school understand my child's special health care needs	9	15.8	10	16.1	8	32.0
9. Information re: current research that might help my child	6	10.0	9	13.2	5	17.9
10. TDD services for hearing impaired	2	40.0	3	27.3	2	50.0
11. Translator/interpreter services	2	50.0	2	33.3	2	100.0
12. Respect for my culture, ethnic identity and religious beliefs	27	57.5	24	64.9	14	73.7
Overall Ease of Service Delivery						
1. Telephone access to providers	30	40.0	38	51.4	17	54.8
2. Access to second opinions	18	27.3	24	39.3	16	59.3
3. Ability to schedule timely specialty care appointments /referrals	26	35.6	31	43.1	16	55.2
4. Waiting time to approve special services/equipment	17	27.9	14	22.2	13	56.5
5. Appeals or grievance procedures	4	12.1	6	15.0	5	41.7
6. Coordination of multiple appointments or visits	24	40.0	19	35.9	12	44.4
7. Required paperwork to access services	25	37.9	18	28.6	9	39.1
8. Handicapped accessibility of physical facilities	22	55.0	20	54.1	6	54.6
9. Transition from adolescent to adult services	4	33.3	2	14.3	2	33.3
10. Waiting time to schedule appts for primary care	39	52.0	38	50.7	17	60.7
11. Waiting time on day of appointment	34	43.6	33	42.3	14	46.7
12. Info on what services are covered by child's plan	24	30.8	30	39.0	12	38.7
13. Flexibility to use cost-effective alternative services, equipment or providers	12	21.1	15	23.8	11	40.7

* *N = the number of respondents who identified a given type of health plan for their child* ***and*** *indicated their child needed or used a particular service. Respondents who indicated that their child is covered by more than one type of ~~health~~ plan or by a health plan categorized as "Other" were not included in the analysis for this table.*

Table 11
Family Voices Survey on Managed Care
Unmet Needs[Ψ] by Type of Health Plan
(N=204)[*]

Type of Health Service	Percent of Respondents within each Type of Health Plan Indicating "Not Satisfied or "Needed, Not Available"					
	HMO		PPO		Not in Managed Care	
Medical and Specialty Services	n	%	n	%	n	%
1. Appropriate routine, well-child care	4	5.3	9	11.7	6	20.0
2. A primary care provider with knowledge of my child's special needs	16	21.1	17	21.8	4	12.5
3. Appropriate pediatric specialty care providers	15	20.0	8	10.4	3	10.0
4. Appropriate pediatric in-patient hospital services	5	8.9	2	3.9	0	0.0
5. Specialized dental care or orthodontic services	27	52.9	16	29.6	4	22.2
6. Physical therapy services	23	45.1	12	20.7	9	33.3
7. Occupational therapy services	27	56.3	20	33.9	8	32.0
8. Speech therapy services	37	56.1	24	35.3	10	34.5
9. Nutritional counseling	16	45.7	20	50.0	5	33.3
10. Psychological testing	15	48.4	17	47.2	7	38.9
11. X-ray and radiology services	2	3.6	0	0.0	2	9.1
12. Laboratory services	4	6.4	2	3.2	3	10.7
13. Genetic counseling services	8	22.2	5	21.7	3	23.1
14. Emergency room services	6	10.2	2	3.7	2	8.3
Mental Health Services						
1. Counseling for child	15	60.0	13	54.2	8	88.9
2. Counseling for family members	28	65.1	17	46.0	9	81.8
3. Family support groups	30	71.4	22	51.2	6	54.6
4. Out-patient diagnostic services	8	40.0	7	31.8	2	25.0
5. In-patient psychiatric care	5	62.5	7	63.6	3	75.0
Other Health Services						
1. Prescription medications	3	4.0	3	4.0	2	6.7
2. Durable medical equipment	8	23.5	6	15.4	3	17.7
3. Adaptive equipment	21	60.0	18	39.1	5	33.3
4. Disposable medical supplies	8	30.8	10	34.5	0	0.0
5. Nutritional products or special diets	14	58.3	14	50.0	3	30.0
6. Home nursing services	11	50.0	6	30.0	1	14.3
7. Personal care attendant services (PCA)	11	68.8	11	55.0	0	0.0
8. Hospice services	3	50.0	3	42.9	0	0.0

[Ψ] *Unmet Need refers to those respondents who indicated they were either "Not satisfied" with the service or that the service was "Needed, but not available"*

[*] *N = the number of respondents who identified a given type of health plan for their child* *and* *indicated their child needed or used a particular service. Respondents who indicated that their child is covered by more than one type of health plan or by a health plan categorized as "Other" were not included in the analysis for this table.*

Table 12
Family Voices Survey on Managed Care
Low Satisfaction with Health Service by Type of Health Plan
(N=204)*

Delivery of Health Service	Percent of Respondents within each Type of Health Plan Indicating "Not Satisfied" Only**					
	HMO		PPO		Not in Managed Care	
Communication and Coordination of Care	n	%	n	%	n	%
1. Information about my child's medical needs	17	21.8	8	10.5	3	9.7
2. Explanation of medical treatments	8	10.3	7	9.0	3	10.0
3. Having time with my child's provider to ask questions	8	10.3	7	9.0	3	9.7
4. Family inclusion in decision-making and planning	9	12.5	6	7.9	3	10.0
5. Child's participation in decision-making and planning	11	20.4	13	24.1	2	10.0
6. Communication between my child's primary care provider and specialty care providers	20	31.3	24	34.8	6	22.2
7. Access to a case manager of care coordinator	26	46.4	25	45.5	3	13.6
8. Helping the school understand my child's special health care needs	31	54.4	35	56.5	7	28.0
9. Information re: current research that might help my child	40	66.7	44	64.7	10	35.7
10. TDD services for hearing impaired	2	40.0	6	54.6	1	25.0
11. Translator/interpreter services	0	0.0	3	50.0	0	0.0
12. Respect for my culture, ethnic identity and religious beliefs	5	10.7	2	5.4	2	10.5
Overall Ease of Service Delivery						
1. Telephone access to providers	16	21.3	10	13.5	2	6.5
2. Access to second opinions	23	34.9	11	18.0	4	14.8
3. Ability to schedule timely specialty care appointments/referrals	15	20.6	15	20.8	4	13.8
4. Waiting time to approve special services/equipment	25	41.0	25	39.7	4	17.4
5. Appeals or grievance procedures	20	60.6	12	30.0	3	25.0
6. Coordination of multiple appointments or visits	13	21.7	14	26.4	4	14.8
7. Required paperwork to access services	17	25.8	16	25.4	6	26.1
8. Handicapped accessibility of physical facilities	5	12.5	5	13.5	2	18.2
9. Transition from adolescent to adult services	4	33.3	9	64.3	3	50.0
10. Waiting time to schedule appts for primary care	7	9.3	9	12.0	3	10.7
11. Waiting time on day of appointment	9	11.5	13	16.7	7	23.3
12. Info on what services are covered by child's plan	27	34.6	19	24.7	7	22.6
13. Flexibility to use cost-effective alternative services, equipment or providers	34	59.7	20	31.8	8	29.6

N = the number of respondents who identified a given type of health plan for their child and indicated their child needed or used a particular service. Respondents who indicated that their child is covered by more than one type of health plan or by a health plan categorized as "Other" were not included in the analysis for this table.

For Communication and Coordination of Care and Overall Ease of Service Delivery, "Needed, Not Available" was not a response option.

THE URBAN INSTITUTE

Younger People with Disabilities and State Health Policy

by Joshua M. Wiener

The views expressed are those of the authors and do not necessarily reflect those of the Urban Institute, its board, its sponsors, or other authors in the series.

Services to younger persons with disabilities (children and adults under 65 years of age) form a substantial share of overall state health spending and are an important part of the Medicaid program. This population accounted for 16 percent of all Medicaid beneficiaries in 1995 (about 5.7 million persons), but 32 percent of Medicaid expenditures (almost $50 billion). Younger persons with disabilities also accounted for nearly one-third of the extraordinary growth in Medicaid spending over the 1988–1995 period. [1] Thus, this population is critical to state efforts to control Medicaid expenditures and to reform health care generally.

This brief discusses a variety of delivery and financing issues that states are facing as they rethink Medicaid and other health programs. A brief overview of the population and the costs associated with health services provided to this group helps set the stage for the discussion.

The Population and Its Service Costs

Younger people with disabilities are a very heterogeneous group, consisting of individuals with physical disabilities, mental illnesses, and mental retardation/developmental disabilities. The number of younger people with substantial disabilities living in the community ranged from 1.0 to 14.1 million people in 1995, depending on the definition used. [2] In addition, about 500,000 younger people with disabilities were in institutions: 135,000 in intermediate care facilities for the mentally retarded (ICF/MRs), 220,000 inpatients in psychiatric institutions, and 150,000 in nursing homes. [3] There is an ongoing trend away from institutional use.

As noted above, the Medicaid program served about 5.7 million younger persons with disabilities in 1995. Spending on blind and disabled Medicaid beneficiaries averaged $8,685 per person in 1995, compared to $1,728 for younger beneficiaries who are not disabled. [4] For the very severely disabled, the cost can be much higher. For example, the average cost of a year's institutional care in an ICF/MR was almost $71,000 in 1995. [5] These institutional costs are particularly high because of extensive quality standards, use of (relatively expensive) unionized state employees in public facilities, and low occu y rates resulting from the deinstitutionalization movement. The average Medicaid cost of servi people with mental retardation/developmental disabilities in home and community-bas Medicaid waivers was just over $24,000 in 1996.

Medicaid expenditures for younger persons with disabilities historically have been about evenly split between acute and long-term care services, but in recent years the balance has shifted toward acute care expenditures. In 1994, 57 percent of Medicaid expenditures for blind and disabled beneficiaries were for acute care, while 43 percent were for long-term care (figure 1).

Service Delivery

States play a much larger role in the direct provision of services for younger people with disabilities than they do for the elderly. They are especially important providers of institutional services for younger persons with mental retardation/developmental disabilities and with chronic mental illnesses. Two major issues concern states as they review their delivery of services to younger people with disabilities: the balance between institutional and home and community-based care and the integration of acute and long-term care services within a managed care system. Both are important features of ongoing debates about cost and appropriateness of care with respect to this population.

Balance Between Institutional and Noninstitutional Services

There is an extremely widespread, although not unchallenged, policy consensus among state policymakers and disability advocates that institutions should play a far smaller role in providing services to younger persons with disabilities than has traditionally been the case. Many advocates go further than policymakers and are unwilling to grant even a residual role for institutional care (which sharply distinguishes the disability movement from advocates for the elderly). There have been numerous lawsuits forcing deinstitutionalization at many state mental hospitals and ICF/MRs. As a result of transferring less disabled individuals to other settings, the remaining residents of state institutions are very severely disabled; moving them to less structured environments may be more difficult and expensive than past shifts. Although the institutionalized population has declined, funds and services have not always followed individuals from the institution to the community.

Home and community-based services are expanding rapidly and embrace an increasingly wide range of services, including home health, personal care, homemaker services, assisted living, adult-foster care, day habilitation, prevocational services, supported employment, supported living, chore service, homemaker services, meals-on-wheels, respite care, family training, modifications to the home, and personal emergency response systems. Many of these services are beyond the traditional definition of "medical care," but are important supports for people with disabilities. As a sign of the shifting balance of care, in 1994 for the first time the number of Medicaid beneficiaries with mental retardation or developmental disabilities receiving home and community-based services exceeded the number of persons receiving care in ICF/MRs. 6

For home and community-based services, two key issues are the flexibility and scope of services and the use of "personal assistance services." Advocates argue that because each person is different, people with disabilities should be able to tailor services to their own needs by choosing from a very broad array of services. In the most far-reaching formulation of this argument, some advocates have proposed "cashing out" services and giving individual consumers total freedom to spend the money as they see fit. Although supporting increased flexibility, federal and state officials worry that, with an ever-widening array of services on the list of offerings, more and more persons with disabilities will come forward to claim services. In an open-ended program like Medicaid, according to this view, people cannot be entitled to "everything" without expenditures increasing greatly.

There is increasing state policy interest in integrating acute and long-term care services through managed care organizations. But debate rages over whether managed care is appropriate for people with disabilities.

Advocates reject this argument, contending that flexibility would lead clients to choose lower-cost, less intensive services than are now forced upon them by the narrower set of services traditionally available.

Closely related to this issue of service flexibility is how much control the client should have over the service provider. This choice is crystallized in the debate over personal assistance services and agency-directed services. Under the traditional agency-directed service approach, an organization hires and directs the personnel who deliver the services. In contrast, in the personal assistance service model, the individual client hires, fires, and directs the service provider. Some states, such as California, have been drawn to personal assistance services because of the potential to lower costs while at the same time giving persons with disabilities greater control over their lives. Other states, however, have been wary of this approach because of potential problems of quality assurance and the administrative complexities. Can persons with severe disabilities enforce acceptable service standards? And can they be counted on to handle income tax, unemployment, Social Security taxes, and workers' compensation contributions for their employees?

Integration of Acute and Long-Term Care Services through Managed Care

Managed care is increasingly being seen as a way for states to control their Medicaid costs. For younger people with disabilities, as with the elderly population, there is increasing state policy interest in integrating acute and long-term care services through the use of health maintenance organizations (HMOs) and other managed care organizations. Initiatives are either under way or being developed in several states (including Wisconsin, Ohio, and Massachusetts). Because costs are so high for persons with disabilities, the potential savings of more efficient service management are large. But debate rages over whether managed care is appropriate for this group.

People with disabilities currently receive their care in a fragmented and uncoordinated system. Proponents argue that applying the principles of managed care can greatly improve the quality of and access to care at the same time that it controls spending. Opponents, including advocates for younger people with disabilities, point out that managed care organizations have very little experience in serving younger people with disabilities and may not be sensitive to their needs or capable of meeting them. The medical necessity criteria often used by HMOs for home care, rehabilitation, durable medical equipment, and therapies are typically much narrower than commonly exist under Medicaid, raising questions of whether these Medicaid-covered services will be provided as required.

In addition, most managed care organizations depend on primary care physicians to reduce use of specialist care. But persons with disabilities often prefer to rely, even for routine care, on specialists who are knowledgeable about their conditions. This factor is potentially aggravated by managed care's restrictions on provider choice, which may mean losing access to the providers best qualified to deal with the problems connected with a specific disability.

Finally, managed care organizations are typically dominated by "the medical profession," i.e., physicians and hospitals. This carries two dangers. Long-term care may become overmedicalized and less consumer directed. And managed care organizations may end up shifting Medicaid resources from long-term care to acute care services.

Financing

States are involved in financing a substantial portion of health care for younger people with disabilities. Medicaid accounts for the lion's share of state health care spending on this population, but a variety of state-only programs provide significant additional funds. As policymakers at the federal and state levels continue to debate ways to restructure the Medicaid program, four financing issues stand out among the many that confront them with respect to younger people with disabilities: the great variation among states in Medicaid spending for this population; the link between Medicaid eligibility and the definition of disability used to qualify for Supplemental Security Income (SSI); the use of Medicaid home and community-based waivers; and the incentives currently facing states to put as many service programs for younger people with disabilities (as well as for other eligible groups) under the Medicaid umbrella as possible in order to partially shift state-only costs to the federal government.

Medicaid Variation among States

State Medicaid programs vary widely in the size of their younger population with disabilities, in total Medicaid expenditures for this population, in the proportions of Medicaid program funds spent on this population, and in per-beneficiary expenditures on this group (Table 1). New York spends considerably more Medicaid dollars on this group than any other state ($7.6 billion in 1994), with California second ($4.3 billion) and Wyoming at the low end ($61 million). Idaho spends the largest share of its Medicaid dollars on younger persons with disabilities (45.6 percent) and Arizona the smallest (16.6 percent). In terms of expenditures per younger disabled beneficiary, Connecticut spends the most ($16,262 in 1994) and Tennessee the least ($3,136).

> ***Advocates of increased state flexibility argue that states have substantial experience with long-term care services for people with disabilities and, according to this view, can be trusted with more latitude.***

Changing Medicaid into a block grant (as was proposed by Congress in 1995) or imposing per-beneficiary caps on spending (as proposed by President Clinton in 1995 and 1997) could lock into place existing interstate differences in spending if allocations or caps are based on historical spending patterns. Without adjustments to loosen the grip of historical spending patterns on federal allocations, there would be no way for low-spending states to come up to the national average, let alone to the levels of high-spending states—and still obtain a federal match. Conversely, high-spending states will be allowed to retain their more generous programs (with the federal match) if they like.

The SSI-Medicaid Eligibility Link

To a large extent, Medicaid eligibility policy drives Medicaid spending. Medicaid eligibility for younger persons with disabilities is tightly linked to the definition of disability used by the SSI program. The SSI rolls have been increasing for both children and nonelderly adults. Between 1988 and 1995, the number of blind and disabled Medicaid beneficiaries increased by over two-thirds (68 percent), partly reflecting the 1990 Supreme Court decision in *Sullivan v. Zebley*, which greatly broadened SSI eligibility for children. [7] The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 tightened SSI eligibility for children. Under current law, however, most children would continue to qualify for Medicaid as low-income children even if they lose eligibility for SSI. [8]

For adults, the SSI definition of disability is based on an inability to work. Many people on SSI have little work experience, reflecting in part a greater likelihood of congenital problems (such as mental retardation). Only about a quarter of disabled Medicaid beneficiaries have enough quarters of work and earnings to be eligible for Medicare before age 65. As a result of the lack of work experience and their disabilities, transition from public assistance to work is difficult and relatively rare. In fact, the linkage of Medicaid eligibility to an inability to work creates a Catch-22 for younger persons with disabilities who might want to work (and the social service agency personnel who want to find them jobs). If Medicaid-funded services help an individual to find and keep a job, then the person is deemed to be no longer disabled, and the very services that enabled him or her to function in the labor market (such as personal assistance services or prescription drugs) are withdrawn after a transitional period because the person will no longer be covered by Medicaid. Without those services, the person may no longer be able to work and will again qualify for SSI and therefore Medicaid. Both the employment and associated Medicaid savings will have been temporary.

Even if younger persons with disabilities are able to find jobs that provide comprehensive private health insurance, this problem is not likely to disappear. Such insurance is unlikely to include the long-term care services covered by Medicaid and may well exclude coverage for preexisting conditions, which this population has by definition. Existing Medicaid provisions that attempt to alleviate these problems have not succeeded in moving many persons with disabilities into the labor force.

Medicaid Home and Community-Based Waivers

All states have Medicaid home and community-based waiver programs for younger persons with disabilities, most commonly for people with mental retardation or developmental disabilities. (Arizona operates a similar program through an 1115 research and demonstration waiver.) Under these programs, states offer a wide range of home and community-based services to a population that is at high risk of institutionalization without these services. In order to obtain federal approval for its waiver, a state must demonstrate that its program will be "cost effective," that is, that the state's average per capita Medicaid costs with the waiver will not exceed its average per capita costs without the waiver. Unlike the rest of the Medicaid program, states may explicitly limit participation in these programs to a predetermined number of people. To help make this possible, the Health Care Financing Administration waives requirements for "comparability" (i.e., the requirement that services be provided to all groups equally) and "statewideness" (i.e., the requirement that all benefits be covered in all parts of the state).

After a reasonably slow start in the early 1980s, home and community-based waiver programs (for both the elderly and disabled) have grown extremely rapidly in recent years, increasing from $735 million in state and federal spending in 1988 to $4,631 million in 1995. Most of the expenditure growth in recent years has been due to the increase in the number of people participating in programs for people with mental retardation/developmental disabilities.

President Clinton has proposed to allow states to implement Medicaid home and community-based service programs on a cost-neutral basis without having to obtain a federal waiver. Advocates of increased state flexibility argue that many of the waiver requirements are needlessly bureaucratic and do not address quality of care. Moreover, states have substantial experience with long-term care services for people with disabilities and, according to this view, can be trusted with more latitude. Although conflict between the federal government and the states over approval of waivers was substantial and bitter during the Reagan and Bush Administrations, regulatory changes implemented by the Clinton Administration have made obtaining waivers fairly routine. Thus, according to this line of argument, little is to be gained by requiring states to go through the federal waiver process.

Opponents of greater state flexibility argue that the current ease of obtaining waivers is precisely the problem. In this view, the Health Care Financing Administration has not been tough enough in requiring that services be cost effective. And because of lax standards, services are often provided to people—especially the elderly—who are not at a high risk of institutionalization. The net result is an inappropriate increase in federal Medicaid spending.

Cost Shifting and Medicaid Maximization

Because states have a substantial commitment to the financing and direct provision of services for younger persons with disabilities, they have a strong incentive to shift the cost of such services to the Medicaid program (where a federal match is available). For example, in 1993, states spent almost as much for non-Medicaid long-term care services for nonelderly people with physical disabilities and nonelderly people with mental retardation/developmental disabilities as they did for Medicaid-financed services. [9] Particularly for services for persons with mental retardation/developmental disabilities, the increased expenditures for Medicaid home and community-based waivers in recent years represented, in part, refinancing of existing state programs. [10] The line between health care and social services, vocational training, and education is fuzzy, especially for long-term care services for the mentally retarded/developmentally disabled and the chronically mentally ill. Thus, vocational training, education, and social services are typically state funded, but if categorized as a Medicaid service will be eligible for a federal match.

Another example of Medicaid maximization is the use of the Medicaid disproportionate share hospital (DSH) program. By federal law Medicaid does not provide coverage for persons between the ages of 22 and 64 who are in "institutions for mental disease" (that is, mental hospitals). Under the DSH provisions of the statute, however, state Medicaid agencies can make extra payments to hospitals that serve a disproportionate share of people who are Medicaid-eligible or uninsured. Some states have made extremely large payments under this provision to their state mental hospitals, using federal Medicaid dollars for the very purpose that is disallowed at the individual beneficiary level under federal law.

> ***It is probably not possible to control Medicaid expenditures over the long run without addressing services and costs for younger persons with disabilities.***

How much further states can shift additional expenses for younger persons with disabilities to Medicaid is unclear. The potential may be limited, at least in the case of services for the mentally retarded/developmentally disabled. Some observers believe that Medicaid home and community-based waiver expenditures will grow more slowly in the future because "further increases are more and more dependent on hard-to-obtain new state matching dollars." [11] In addition, the Omnibus Budget Reconciliation Acts of 1990 and 1993 effectively capped increases in spending on DSH payments.

Conclusion

Younger persons with disabilities account for a substantial portion of state health spending. It is probably not possible to control Medicaid expenditures over the long run without addressing services and costs for this population. As states consider their health programs for younger persons with disabilities, there are at least five points to keep in mind:

- ☐ Given the high Medicaid costs of persons with disabilities, it is likely that states will enroll greater numbers of persons with disabilities into managed care. To date, however, managed care organizations have not had much experience with low-income persons with mental retardation, mental illness, or serious physical impairments. Efforts to quickly enroll large numbers of people with disabilities into managed care run the risk of either not producing the expected savings or reducing the quality of care that enrollees receive.

- ☐ As with the rest of the Medicaid program, spending on younger persons with disabilities varies tremendously across states, both in terms of total dollars and spending per beneficiary.[12] Without substantial adjustments, Medicaid block grants or caps on the rate of growth in per-beneficiary spending will lock into place existing variations, making it impossible for low-expenditure states to reach the levels of states that currently spend more.

- ☐ There is a tension between covering a broader range of services and the open-ended entitlement structure of Medicaid. While disability advocates argue that, with a very broad menu of services, persons with disabilities will use cheaper and fewer services than professionals would choose, budget officials worry that a broader range of services will lead to higher utilization and substantially greater expenditures. The Medicaid home and community-based waivers put fiscal constraints on an otherwise very large potential demand by limiting the number of people who can receive services. At its extreme, a Medicaid block grant without an individual entitlement to coverage would give states maximum flexibility to provide flexible benefits without having to worry about entitlement-driven increases in demand driving up expenditures. The danger in this scenario is that funding will be inadequate to provide services to all the persons with disabilities who meet current eligibility criteria.

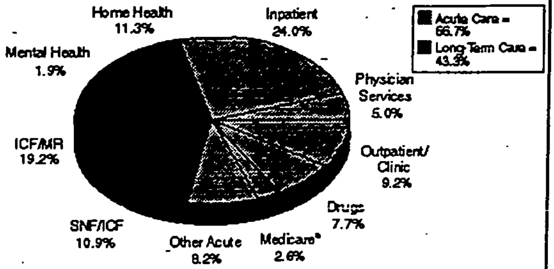
- ☐ Efforts to move SSI beneficiaries into the workforce face special difficulties. Persons with disabilities are particularly dependent on Medicaid and other services that come with being "unable to work." Movement into jobs can mean the loss of the very benefits they need.

- ☐ Because the costs of serving persons with disabilities are so high, there is a strong incentive on the part of the states to shift costs to the federal government. Many states have refinanced their state-funded programs for younger people with disabilities by moving them into the Medicaid program, thus gaining a federal match for those state (and sometimes local) expenditures. Some states have used the federal match to expand services; others have taken the opportunity to cut back on their own spending. How much more state and local spending on younger persons with disabilities can be shifted to the federal government could have a strong influence on the rate of increase in Medicaid spending in the years ahead.

Tables, Figures, Charts and Graphs

Figure 1

Medicaid Expenditures for Younger Beneficiaries Ages 0 to 64 with Disabilities, by Type of Service, 1994



Total Expenditures = $45.3 billion

Source: Urban Institute 1997, based on HCFA 2082 and 64 data for nonelderly blind and disabled beneficiaries.

Notes: Does not include administrative costs, accounting adjustments, or the U.S. territories. Totals may not add to 100 due to rounding. "Other Acute" care services include case management, family planning, dental, EPSDT (health screening for children), vision, other practitioners' care, etc. "ICF/MR" refers to intermediate care facilities for the mentally retarded. "SNF/ICF" refers to skilled nursing facilities/other intermediate care facilities.

a. Medicaid payments to Medicare are distributed proportionately among aged, blind, and disabled beneficiaries. The 2.6% figure is the share for the blind and disabled.

Table 1

Medicaid Beneficiary Totals and Expenditures for Younger Persons Ages 0 to 64 with Disabilities, 1994, by State

State	Younger Beneficiaries with Disabilities (thousands)	Expenditures on Younger Persons with Disabiliti	
		Total (millions of dollars)	Share of Total Medicaid Expenditures (percent)
Alabama	125	$541.3	30.6%
Alaska	6	76.5	26.6
Arizona	56	260.2	16.6
Arkansas	83	482.8	44.9
California	704	4,339.8	30.9
Colorado	39	376.7	33.7
Connecticut	50	809.6	33.4
Delaware	11	125.0	44.5
District of Columbia	22	311.2	39.4
Florida	251	1,605.2	30.0
Georgia	177	1,105.3	33.8
Hawaii	18	137.7	30.1
Idaho	17	142.3	45.6
Illinois	260	2,352.3	44.5
Indiana	67	817.9	29.1
Iowa	47	443.3	40.7
Kansas	36	340.2	34.7
Kentucky	145	790.5	42.3
Louisiana	136	1,174.3	28.9
Maine	33	292.0	31.3
Maryland	81	846.6	37.7
Massachusetts	137	1,636.3	34.8
Michigan	213	1,767.9	35.9
Minnesota	65	910.9	36.9
Mississippi	117	475.7	35.8
Missouri	92	630.0	24.9
Montana	15	151.3	43.9
Nebraska	22	213.7	34.7
Nevada	14	139.0	33.3
New Hampshire	13	159.2	19.2
New Jersey	137	1,641.6	34.3

New Mexico	34	261.3	39.3
New York	471	7,646.6	36.0
North Carolina	113	896.3	28.2
North Dakota	8	108.9	39.0
Ohio	220	1,839.1	33.4
Oklahoma	52	350.7	33.7
Oregon	44	392.4	35.5
Pennsylvania	264	1,930.6	30.0
Rhode Island	25	304.7	38.7
South Carolina	88	588.2	30.9
South Dakota	12	128.5	44.2
Tennessee	203	635.5	23.6
Texas	251	1,940.4	23.8
Utah	17	177.6	34.6
Vermont	14	110.0	38.7
Virginia	97	624.2	33.4
Washington	101	898.4	35.3
West Virginia	67	444.2	35.4
Wisconsin	104	882.9	39.1
Wyoming	5	61.0	38.5
U.S. Total	5,381	45,317.9	33.1

Source: Urban Institute 1997, based on HCFA 2082 and 64 data for nonelderly blind and disabled beneficiaries.

Note: Expenditures do not include administrative costs or accounting adjustments, or the U.S. territories. Medicaid payments to Medicare are proportionately among aged, blind, and disabled beneficiaries. This table includes the share for the blind and disabled.

Notes

1. See John Holahan and David Liska, "Reassessing the Outlook for Medicaid Spending Growth," New Federalism: Issues and Options for States, Series A, no. A-6 (Washington, D.C.: Urban Institute, March 1997).

2. Joshua M. Wiener and Catherine M. Sullivan, "Long-Term Care for the Younger Population: A Policy Synthesis," in Joshua M. Wiener, Steven B. Clauser, and David L. Kennell, *Persons with Disabilities: Issues in Health Care Financing and Service Delivery* (Washington, D.C.: Brookings Institution, 1995), pp. 291-324.

3. Wiener and Sullivan, "Long-Term Care for the Younger Population"; Gary A. Smith and Robert M. Gettings, *The Medicaid Home and Community-Based Waiver Program: Recent and Emerging Trends in Serving People with Developmental Disabilities* (Alexandria, Va.: National Association of State Directors of Developmental Disabilities, 1996).

4. Holahan and Liska (1997).

5. Smith and Gettings (1996).

6. Ibid.

7. Holahan and Liska (1997).

8. See Leighton Ku and Teresa A. Coughlin, "How the New Welfare Reform Law Affects Medicaid," New Federalism: Issues and Options for States, Series A, no. A-5 (Washington, D.C.: Urban Institute, February 1997).

9. Office of the Assistant Secretary for Planning and Evaluation, *Cost Estimates for the Long-Term Care Provisions under the Health Security Act* (Washington, D.C.: U.S. Department of Health and Human Services, 1994).

10. Smith and Gettings (1996).

11. Ibid., p. 19.

12. For further variation in Medicaid spending generally, see John Holahan and David Liska, "Variations in Medicaid Spending among States," *New Federalism: Issues and Options for States*, Series A, no. A-3 (Washington, D.C.: Urban Institute, January 1997).

About the Author

Joshua M. Wiener is a principal research associate at the Urban Institute's Health Policy Center. His specialties are Medicaid, health care for the elderly, and long-term care. He came to the Urban Institute in 1996 from The Brookings Institution. His most recent book is Persons with Disabilities: Issues in Health Care Financing and Service Delivery (Washington, D.C.: Brookings Institution, 1995).

Home

How to contact the Urban Institute.

How to order Urban Institute Publications.

BAZELON
CENTER
MENTAL
HEALTH
LAW

Protecting Consumer Rights in Public Systems'

MANAGED MENTAL HEALTH CARE POLICY

A Series of Issue Papers on Contracting for Managed Behavioral Health Care

#1

DEFINING "MEDICALLY NECESSARY" SERVICES TO PROTECT PLAN MEMBERS

March 1997

As Medicaid, mental health and child welfare systems are redsigned to adopt a managed care approach to the organization and delivery of services, important shifts occur in how services for adults and children with mental health care needs are regulated. This paper has been prepared by the Bazelon Center for Mental Health Law for the Center for Mental Health Services and concerns public agency contracts for managed behavioral health care.

This paper addresses a critical part of any such contract, the definition of what is a medically necessary service and the procedures used to determine when a service is medically necessary. "Medically necessary" criteria should require that services are designed to achieve appropriate goals and delivered in a manner adhering to state standards and principles. The criteria should result in appropriate access to the defined benefit package.

The paper is designed to assist consumers, families and advocates, as well as policymakers, to ensure that "medically necessary" standards in public-sector contracts for managed mental health care[1] protect consumers. It particularly emphasizes the rights and needs of adults with serious mental illness and children with serious emotional disturbance.

BACKGROUND

Historically, public sector mental health services have been funded either through fee-for-service reimbursement or with funds received under a grant from local, state or federal governments. Now, increasingly, governments at all levels[2] are moving toward contracting out management of the mental health system, and often the entities entering into these contracts are private for-profit companies. In some states they are

A POLICY ANALYSIS SERIES FROM THE BAZELON CENTER FOR MENTAL HEALTH LAW
1101 15th Street NW, #1212, Washington DC 20005 • 202/467-5730 • TDD467-4232 fax 202/223-0409 • HN1660@handsnet.org • www.bazelon.org

nonprofit providers or groups of providers that have joined together as a more comprehensive managed care entity.

This shift to managed care alters incentives in the system. Typically, managed care firms agree to provide an array of services (specified in the contract) to a defined group of individuals (also described in the contract) for a flat fee or payment negotiated in advance. Most often, the plan receives a capitation payment for each individual enrolled. The incentives under these arrangements are for managed care entities to control their costs. If they provide fewer services, they will make more profit or save more money. This directly, and deliberately, creates the opposite incentive to that in a fee-for-service system, where providers' income increases if more services are furnished. Yet, while controlling costs is an important objective for the public agency, it must be balanced with legal protections for covered individuals so that consumers have appropriate choices and are not denied services in order to save expenses or increase profit.

The shift to managed care often alters the providers' role in subtle ways as well. In a fee-for-service system, the provider's clinical judgment was largely insulated from cost-saving concerns, and when the Medicaid agency denied reimbursement, the denial was a clear-cut event which triggered a formal notice and the opportunity for appeal. Under these circumstances, the individual could often rely on the provider to support the appeal. Under managed care, the provider's role is more ambiguous, and the consumer may not have as clear a picture of the service options that can be considered or any understanding that a service has, in fact, been denied him by the treating provider. For the consumer, there is no clear "denial event" and, as a result, less opportunity for an appeal.

The shift from rules and regulations to contracts also represents a dramatic change, and requires the recrafting of essential principles for the service system into contract language. In this process, crucial aspects of the current system could be lost if not specifically included; yet the process also provides an opportunity to improve upon and strengthen the current system. Fundamental for developing sound contracts for public mental health services are the following principles:

◆ Even where the mental health system has been privatized, the ultimate responsibility for its operation still lies with the public agency. This includes ensuring compliance with federal and state law.

The research for this paper was supported by the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

◆ State plans for the mental health system developed prior to the shift to managed care, and generally developed with significant public input, should be considered when moving to a restructured system. There is no need to reinvent the wheel if these plans are still appropriate, although at the same time improvements can be made.

◆ Consumers, family members and advocates should continue to have a voice in how the system is designed and run, and their knowledge of how systems can best serve consumers and families should be drawn upon. State planning processes, open public forums and other opportunities for public comments should not be discarded as the state develops requests for proposals (RFPs), reviews bids and negotiates contracts.

WHAT IS "MEDICALLY NECESSARY" IN MANAGED CARE SYSTEMS?

Medical necessity is not a new concept. It has been used in Medicaid, Medicare and private insurance rules for many years, and managed care plans operating in the private sector typically use procedures to decide whether a particular ser-vice is appropriate, effective and necessary for the individual.

Managed care plans agree to deliver covered services to covered individuals whenever those services are needed. They generally cannot refuse to serve an individual designated as a member of their plan, as can most agencies operating under a grant or fee-for-service system. Managed care plans therefore devise mechanisms for making decisions about what services to provide to whom, under what circumstances. Otherwise, the plan would have no control over utilization and expenditures and could not operate effectively.

Managed care plans use different mechanisms to control the use of services and hold down their costs. One way is to negotiate discount rates to pay their providers. However, Medicaid rates are generally low to begin with, so plans must also create greater efficiency through stringent controls on the use of care. Some put their provider network under pressure to control costs by making capitated payments to the providers, thereby passing on to them a substantial part of the risk. (Providers at risk face the possibility that revenues will not be sufficient to cover expenditures incurred in the delivery of necessary services.) In some managed care plans, as in fee-for-service, specific limits are placed on the duration of care (such as no more than 20 outpatient sessions or 30 inpatient hospital days per year).

More frequently, however, managed care plans operate without arbitrary upper limits on the length of specific treatments, and instead provide care in an individualized manner. To do this, they set up internal systems to determine when a service is medically necessary for a particular individual. Utilization review and prior authorization are two common mechanisms for doing this.[3]

"Medically necessary" definitions, in effect, set the boundaries between what the managed care contract will cover and what is left as the public agency's continuing responsibility (such as housing, job training, etc.)—or as no one's responsibility at all.

Definitions of "Medically Necessary" Services

Before creating a state definition of medically necessary services, it is important to understand Medicaid law and regulations and the courts' interpretations of those rules.

Because, broadly speaking, individuals have no legal right to mental health services provided by the government, access to mental health services and supports is at government discretion.[4] The Medicaid statute defines the rights and entitlements of eligible individuals. Eligible individuals are entitled to the array of health and mental health services and supports described in the state Medicaid plan. For adults, beyond a minimal list of mandatory services, states generally have the flexibility to provide only the services in the state Medicaid plan. Children have a greater entitlement. Medicaid law requires states to furnish children "necessary health care, diagnostic services, treatment and other measures (authorized under Medicaid law) to correct or ameliorate defects and physical and mental illnesses and conditions...whether or not such services are covered under the state plan."[5]

When states shift to managed care, the waiver plan approved by the federal Health Care Financing Administration supersedes the state Medicaid plan as the basic document defining eligible individuals' right to services. However, even under a waiver, certain aspects of Medicaid law remain in effect, including federal requirements concerning the provision of medically necessary services.

Medicaid law permits states to define the "amount, duration and scope" of any covered service and to "place appropriate limits on a service based on such criteria as medical necessity or on utilization control procedures."[6]

This means, for example, that states may require authorization to be obtained prior to receipt of services or may limit certain procedures only to those for whom they are appropriate. However, while states may limit services, based on medical necessity, their discretion is not unbridled. Medical necessity cannot be used to deny needed services arbitrarily or to discriminate invidiously in the provision of services.

Medicaid law requires that a covered service be provided in sufficient amount, duration and scope "to reasonably achieve its purpose."[7] States are also prohibited from denying or reducing the amount or scope of covered services based on an individual's diagnosis, type of illness or condition suffered.[8]

Some courts have held that a broad interpretation of the term "medical necessity"[9] is required to carry out the remedial goals of the Medicaid program.[10] Perhaps the most thoughtful of these decisions is *Visser v. Taylor*, in which a federal judge ordered the state of Kansas to provide Medicaid payment for the prescription drug Clozapine when a doctor had determined that it was the last remaining therapy appropriate for his patient. The court wrote:

> *The touchstone of the [amount, duration and scope cases] is medical necessity. Federal statutes and regulations providing for medically necessary treatment are to be liberally construed in favor of the intended beneficiaries of the Medicaid program.... The determination of whether a treatment is medically necessary, for purposes of Medicaid, is a professional judgment which must be decided and certified by the treating physician. A state may not eliminate funding for medical services certified by a qualified physician as being medically necessary.*[11]

The U.S. Supreme Court has not squarely addressed the issue, but in *Beal v. Doe*, it expressed serious concerns about state Medicaid plans that did not include medically necessary treatment in their coverage:

> *[S]erious statutory questions might be presented if a state Medicaid plan excluded necessary medical treatment from its coverage.*[12]

Courts have also considered the process by which "medically necessary" determinations are made and have held that, in enacting the Medicaid program, Congress intended to invest broad discretion in treating physicians, but not others, to determine what treatment is medically necessary. For example, in *Weaver v. Reagen*, a federal appeals court ordered the state of Missouri to fund AZT treatment for Medicaid recipients with AIDS whose doctors had determined that the treatment was medically necessary. The court declared that:

> *The Medicaid statute and regulatory scheme create a presumption in favor of the medical judgment of the attending physician in determining the medical necessity of treatment.*[13]

In an earlier decision, this same court held:

> *The decision of whether or not certain treatment or a particular type of surgery is 'medically necessary' rests with the individual recipient's physician and not with clerical personnel or government officials.*[14]

Thus, federal rules, supported by court decisions, prevent states from limiting access to Medicaid services through arbitrary means that have the effect of denying care solely because of the diagnosis or type of illness or condition.

Federal rules, again supported by court decisions, also require states to protect consumers' access to services that are necessary to "reasonably achieve their purpose,"[15] and courts have required that these decisions rely heavily on treating physicians' judgments, and that they not be made by clerical personnel or government officials.

States cannot meet these responsibilities if they cede to a managed care entity the full responsibility for determining when a service will be considered medically necessary.

Finally, other aspects of Medicaid law affect the process of making final determinations regarding the necessity of a service. Medicaid has a defined system for appeals and fair hearings for Medicaid-covered individuals, and these rules cannot be overridden by a move into managed care.

Who Should Define What Is Necessary?

States, as guardians of the public trust, must themselves both decide what services are to be covered in the plan (i.e., define the benefit package) and set the parameters as to who receives these services, when and for how long. It is the state, with appropriate public input, that must develop as part of its contracting process the specific definition used to determine when services are medically necessary.

One option would be for the legislature to define the term and then require that managed care contracts be consistent with this legislative definition. Alternatively, the state agency (either Medicaid or mental health authority) could define the term.

Contracts now in place between states and managed care entities show a disturbing trend. Although states frequently provide detailed descriptions of a broad benefit package that covers a wide array of appropriate services, contracts generally provide little, if any, guidance to managed care firms regarding appropriate decisions on the necessity of care. Some states have no definition at all of "medically necessary."[16] As a result, managed care plans are deciding, with little or no public input, requirements or oversight, who will be served, how long they will receive services, which services they will receive and how much money will be spent on their care.

In addition to creating its own definition of "medically necessary," the state should expect that managed care plans, as they implement that definition, will set more detailed and condition-specific criteria. States should therefore require that the plan's internal rules for implementing the state's definition, such as practice guidelines, be made available both to the state and to advocacy groups in the state. In this manner, the plan's operating criteria can be reviewed to ensure that they meet the state's expectations with respect to the provision of services.

Consumer, family and advocacy groups are increasingly concerned about whether managed care for mental health services will allow individual choice and be provided in sufficient amount to meet individual needs. These groups are now organizing to influence many aspects of their state's RFP and contract, including the definition of "medically necessary." Many states are now recognizing the need to consult consumers, families and advocates about the contracts. Since these documents will govern the public system for years to come, their success depends on their support by important stakeholders in the state.

PROBLEMS WITH THE CURRENT APPROACH

There are some serious problems with the current state contracts concerning medically necessary care. Most are not specific enough and grant managed care companies too much discretion. As a result, states may leave themselves liable for mandated Medicaid services that the plans will not provide—in particular, services that go beyond the plan's very traditional concepts of what is necessary.

Most contracts between states and managed care entities provide minimal guidance on what is to be considered a medically necessary mental health service. Some have no definition at all of this important phrase. This gives the managed care entity extremely broad discretion to determine what services will be furnished to individual members of the plan at particular times and can also lead to confusion among members as to what services ~~they are~~ entitled to receive. In some cases, the state will find that mandated Medicaid services are not being provided through the managed care entity and that this is quite legal under the contract. In that situation, the state will remain legally obligated to continue to provide the covered service through some other means.

A review of extant definitions of "medically necessary" finds three broad categories: one set of definitions that are extremely basic and medically focused, with no mention of mental health or behavioral health services; a second set of definitions that include references to mental health or mental disorders, but are still clinically focused; and finally some definitions that adopt a more comprehensive approach referencing social supports and services to ensure high functioning and quality of life.[17]

Most states provide only basic descriptions of what they consider to be medically necessary services. Current state definitions use language that is almost boilerplate, describing medically necessary services as those needed to diagnose and treat certain illnesses or conditions. They often include the qualifications required for providers and require that services reflect good practice and are expected to be effective. Generally they encourage provision of services only if there is not an equally effective but less costly alternative. Many of these definitions also identify services that the state does *not* consider medically necessary.

This language leaves significant discretion with the managed care plan. As a result, many plans initially have chosen to operate their public-sector contracts under standards similar to those they use for their private-sector business clients. However, an employed population's need for behavioral health services can be very different from the needs of individuals in public systems. Managed care plans in the private sector heavily emphasize short-term hospital stays, traditional outpatient therapy and the use of medications. While these are important components of a comprehensive system of care, they are far from the full array of services necessary for adults with serious mental illness and children with serious emotional disturbance. As a result, under these plans, people enrolled in public-sector managed care tend to have access only to a limited part of the Medicaid benefit package the state has created.

Medicaid law authorizes a broad array of services that go far beyond narrowly defined "medical" care. Under Medicaid, individuals are eligible for prevention, treatment, rehabilitation and support services (such as case management, family education, social-skills training and family support services). Increasingly, a wide array of the services needed by adults with serious mental illness and children with serious emotional disturbance who depend upon the public sector have been provided under Medicaid.

Especially disturbing is language in several contracts that services need not be provided if the member fails to comply fully with the medical regime established by a physician or other provider of services. This not only limits choice, but can divert attention from issues that reflect problems of the service system, rather than being the fault of the individual member. In addition, this language can be interpreted as overruling the plan's requirement to provide services when needed.

Problematic language in some contracts permits plans to use community, rather than national, standards of practice in making decisions. This language may be used to deny services that are not available within the community, even though that service may be the most appropriate choice. This is especially likely to occur in rural communities, where services are currently more sparse.

TAKING A DIFFERENT APPROACH

Managed care plans define "medically necessary" services in a very concise and limited way. These definitions are typically only a few lines long, making it impossible to take more than a very limited approach. In the public sector, on the other hand, definitions of what constitutes an appropriate service for reimbursement, although not termed "medically necessary," are much longer and more detailed. They encompass considerably more than "medical" services in the strict definition of the term, and they address a host of service-delivery issues, such as requiring care be furnished in the least restrictive setting and in a culturally competent manner.

As managed care techniques are adopted for the public sector, it is neither appropriate nor advisable for public agencies to take traditional managed care definitions as their model. They have no reason to limit their definition of medically necessary services to a few lines, perforce omitting essential elements of good public-sector care.

States should instead use the "medically necessary" definition to protect consumers' choice and access to high-quality services, furthering the overall goals of their mental health system. To achieve this, states need to design detailed definitions of medically necessary services.

A wide array of commonly used treatments and rehabilitation approaches is effective for individuals with mental illness—in some circumstances and for certain conditions. Research indicates that no single approach is universally superior, and few treatment approaches can be eliminated as universally ineffective. The most important characteristic of an effective mental health service system is the appropriate matching of services and need, based on individual clinical conditions and circumstances and individual choice. This means that listing benefits alone is not sufficient to produce good outcomes.

The benefit package can provide incentives that will encourage desired patterns of utilization to enhance effective care, such as substituting lower-cost equivalent services. However, a judicious mix of benefit design and individualized decisionmaking is still needed to match individuals and services correctly. Benefits must therefore be flexible, and financial incentives promoting lower-cost services that are equally or even more effective in the long term (such as in-home services, consumer-run services, assertive community treatment and medications) must be balanced by controls on the use of such services by individuals who do not need them. Selecting the right match of services to effectively address the plan member's individualized problems, while respecting the member's preferences, is the purpose of "medically necessary" criteria.

To accomplish this end, this paper suggests a different approach to defining medically necessary services—one more consistent with the law. In place of broad but short stipulations requiring plans to ensure that services adhere to professional standards, are safe and effective and emphasize less costly alternatives (as the typical contract definition does today), states could incorporate more of the essential values and directions they desire from their mental health service system. The section of the contract that deals with when a service is medically necessary should then stipulate:

- the desired goals of services (e.g., to promote recovery);
- the range of services that are to be considered "medically" necessary (e.g., rehabilitation as well as clinical treatment);
- principles for service delivery (e.g., members should be fully engaged in services planning and be given choices); and
- that plans are prohibited from subverting desired goals through arbitrary restrictions on amount, duration and scope of services.

The definition of medically necessary services should also include standards for the process of making these determinations. Further, a system of member appeals should be linked to the definition. Standards for the appeal system can then be set elsewhere in the contract. Some states may also wish to include stipulations of what is *not* considered to be a medically necessary service (e.g., custodial care). In plans that cover children and adolescents as well as adults, the specific needs of children should be addressed.

This approach incorporates links between the definition of medically necessary services and other contract stipulations. Too often, the medical-necessity definition has little or no connection to other requirements in the final contract. The definition of "medically necessary" must be linked to (or re-state) the state's concepts regarding individual rights, the benefit package, approaches to service delivery, quality of care and mechanisms for appeal. Cross-referencing these items in the medical-necessity definition would greatly enhance the state's ability to enforce the standards in individual cases. The medical-necessity definition is then more grounded in the underlying principles and standards of the contract, and the state ensures that other important provisions of the contract will be considered as a plan reviews whether a particular service is medically necessary

CREATING A DEFINITION OF "MEDICALLY NECESSARY"

The following material is not intended to be a model definition. Instead, it presents the elements of a definition and provides suggestions, meant to be useful and provocative, for specific clauses in the contract.

WHAT IS MEDICAL?

The narrow array of services traditionally offered by managed care plans has led to discussions about changing "medically necessary" to a term that might suggest a broader range of services. Several have been recommended, such as "clinical necessity," "social necessity" (particularly for child welfare systems) or "bio-psychosocial necessity." Another option is to drop the adjective and cover all "necessary" services.

However, changing the terminology is probably neither required nor advisable. With the wrong definition, any term will fail to protect consumers. The key to ensuring appropriate delivery of care is to have the right criteria. With the right definition, "medical" necessity is preferable because it builds on current Medicaid law that considers a wide array of services to be "medically necessary."

It is important to note that Medicaid itself recognizes a range of services as "medical." Under Medicaid, nonmedical clinical services (i.e., services of psychologists and psychiatric social workers), case management, rehabilitation, personal assistance, speech therapy and occupational therapy are reimbursable. Using the term "medically necessary services" in a Medicaid context therefore does not substantially limit the range of mental health services covered.

Defining Elements of a Definition of "Medically Necessary"

Below is a proposed definition of medically necessary services for inclusion in managed care contracts, based on the approach suggested here. The sections that follow lay out issues to address under each facet of the definition, illustrating the new approach with suggested language. This material is not intended as a "model" definition. Each state definition will need to be crafted individually to reflect the unique aspects of a state's current legal code, goals, consumer, family and advocate aspirations, and the organization of the state's service system.

Definition of Medically Necessary Services

A medically necessary service is a service:

- *furnished in accordance with the goals of services, described in paragraph (A);*
- *furnished for the specific purposes described in paragraph (B);*
- *that meets the standards of service delivery in paragraph (C); and*
- *that, in the case of individuals under age 21, meets the additional standards in paragraph (D).*

Medically necessary services shall be provided in accordance with paragraph (E), which prohibits arbitrary actions by the contractor to limit services, and through a process that meets the requirements in paragraph (F) and shall be appropriately linked to the grievance and appeal system as required in paragraph (G).

A. *Goals of Services*

The first question a "medically necessary" definition must answer is: necessary for what end? Services and supports are provided to achieve certain goals, both for the individual and for society. Articulation of these goals in the medical necessity definition will enable the state to clearly articulate the overall objectives of its mental health system and provides the foundation for addressing other critical issues.

Many states have articulated goals in their waiver plans or requests for proposals, and a few include them in their contract language. However, including this language in the contract does not necessarily create a legally binding requirement on the managed care plan. To achieve that goal, the definition should directly reference the goals of services.

Each covered individual (Member) shall be eligible for services, as defined in section ____, provided in sufficient amount, duration and scope to enable Members to function at the highest possible level, given the severity of their disorder, in the least restrictive setting of their choice, and for children under age 21, to progress developmentally as individually appropriate.

Medically necessary services:

(a) are designed to promote recovering and healing, enhance quality of life, promote wellness and improve functioning;

(b) are provided with the goal of ensuring that Members are successful and satisfied in the setting of their choice, with the least amount of ongoing professional intervention;

(c) reflect Member choice and are designed to achieve outcomes desired by the Member;

(d) are offered in the most integrated settings appropriate to the Member's needs;and

(e) for Members under age 21, enable the child to progress developmentally as individually appropriate, designed to enable the child to live at home or in a homelike setting, and address both the needs of the child and the related needs of the family.

B. Purpose of Services

In addition to being directed towards the advancement of members' life goals, services must be designed to accomplish certain objectives. Additionally, the definition of medically necessary services must be explicitly broad and encompass not only clinical treatment but also screening, prevention and rehabilitation. Most state definitions address these issues to some degree and the language below is based on language that appears in several state definitions of "medically necessary."

A medically necessary service shall mean a service identified in Section ____ (Benefit Package), and supplies and technologies furnished by or under the supervision of a physician or other licensed practitioner of the healing arts within the scope of their ~~practice under~~ State law, that are provided consistent with the Member's desires and wishes and in sufficient amount, duration and scope to effectively:

(a) screen and assess the presence of a mental illness condition;

(b) identify and evaluate a mental illness that is suspected;

(c) treat, ameliorate, diminish or stabilize symptoms of mental illness, including impairment in functioning;

(d) alleviate suffering or pain;

(e) prevent, arrest or delay the development or progression of a mental illness and to prevent or delay relapse;

(f) provide rehabilitation to enable the Member to attain or maintain an optimal level of functioning (including functioning in all important areas of life, such as daily activities, social relationships, and independent living);

(g) affirmatively ensure access to and promote appropriate utilization of services (including overcoming barriers caused by inability to obtain transportation).

C. *Standards of Service Delivery*

In addition to describing the goals and purposes of services, the definition of "medically necessary" should ensure compliance with important services delivery standards. For example, the definition should make clear that medically necessary services must be responsive to members' unique needs, provide choice among possible alternatives, and be furnished in an appropriate manner. Such standards are incorporated into law in many states or reflected in mental health system planning documents.

Medically necessary services must be:

(a) based upon an individualized assessment of the individual's assets, strengths, desires, needs and environmental supports;

(b) furnished in accordance with an individualized services plan, which is based on a comprehensive assessment, developed in partnership with the Member (or in the case of a child, the child to the extent feasible and the child's family) and designed to attain specific outcomes desired by the Member; the services plan shall be monitored, reassessed and revised periodically, based on progress, outcomes and consumer satisfaction; Members shall be given ultimate authority to review and approve the services plan;

(c) services of the Member's choice (or, in the case of a Member child unable to make choices, services of the Member's family's choice). The Member has the right to refuse services consistent with law and such refusal may not be used as grounds to deny other services; the plan may deny services that would be ineffective or for which there is a cost-effective alternative that oth-

erwise satisfies the standards for medically necessary services, as set forth herein and in Sections (A), (B), (D), (E), (F) and (G);

(d) in conformance with any psychiatric advance directive the Member has prepared;

(e) delivered in a timely manner, with an immediate response in emergencies in a location that is convenient and accessible to Members;

(f) responsive to unique needs of linguistic and cultural minorities and furnished in a culturally relevant manner;

(g) responsive to the unique needs of people with mental and physical impairments and furnished with accommodations to their needs, as required under the Americans with Disabilities Act and other applicable law;

(h) provided in the least restrictive appropriate setting; inpatient and residential treatment shall be used only when all less restrictive levels of treatment have been unsuccessful or cannot be safely provided;

(i) provided in the Member's home or home community, except in limited extraordinary circumstances;

(j) designed (when relevant) to prevent the need for involuntary treatment or institutionalization;

(k) provided in a manner that facilitates continuity and coordination of services within a system of care;

(l) furnished so as to include referrals to and coördination with agencies providing other relevant services to the Member, including providers of other health care services, social service providers, education providers, preschool and child care providers and vocational rehabilitation providers;

(m) consistent with national standards of practice, including standards of practice in community psychiatry and psychiatric rehabilitation, as defined by standard clinical references, generally accepted professional practice or empirical professional experience;

(n) consistent with the plan's Quality Assurance standards and procedures, and its placement criteria, in Sections _____ of the contract; and

(o) consistent with the standards for confidentiality in Section ____ of the contract.

D. Additional Standards for Children

Not all managed behavioral health care plans include children. In some states, children's services are left in the traditional state system or provided through a separate managed care plan. Any managed care plan that covers children and adolescents must address several unique issues.

This paper highlights children's issues here, but these issues could be addressed by incorporating them in sections (B) and (C) above.

Under Medicaid law, children are entitled to Early and Periodic Screening, Diagnosis and Treatment, which must include access to any federally reimbursable Medicaid service, regardless of whether it has been included in the state plan. Definitions of "medically necessary" must reflect this legal entitlement for children.

Thus, the definition of "medically necessary" must make clear that: (With respect to the issues under (B) above):

Members under age 21 shall have access to all services reimbursable under Title XIX of the Social Security Act.

For Members under age 21, the Member's individualized services plan shall be coordinated with the child's Individualized Education Program (IEP) or Individualized Family Service Plan (IFSP); the plan shall consider services covered in the child's benefit package to be medically necessary by virtue of their inclusion in the IEP or IFSP.[18]

In addition to the purposes identified in Section (B), services are medically necessary if furnished to Members under age 21 for the purpose of:

(i) identifying mental illnesses or conditions, and to identify children at risk of such conditions as a result of the identified specific risk factors cited in Section ____ of the contract;

(ii) ameliorating or correcting a condition identified during a periodic or interperiodic screen; and

(ii) provide anticipatory guidance to parents of children with respect to mental health and emotional development.

(With respect to issues under (C) above):

In addition to the standards of service delivery identified in Section (C), services to Members under age 21 must:

(a) be provided as early as possible in the child's life in order to prevent or identify potential conditions in their early stages;

(b) be provided in accordance with a services plan developed with the participation and approval of the appropriate family member(s). For children with serious emotional disturbance, the plan shall integrate family education and support services, as defined in section ____;

(c) include notification, at least annually, of families or enrollees under the age of 21 of the availability of comprehensive preventive and interperi-

odic screens on a regular basis, as defined in the Benefit Package in section ___;

(d) emphasize and promote developmental progress of the child, as individually appropriate; and

(e) be delivered in the most natural environment possible, which for Members' under age 21, in addition to home and community settings, shall include child care centers or preschool programs.

E. Arbitrary Limits

Managed care is a delivery mechanism intended to facilitate individualized care decisions. Placing arbitrary caps on mental health services, such as limiting outpatient sessions to 20 or hospital days to 30 per year, is inconsistent with individualization and often results in the denial of necessary care.

On the other hand, in place of caps, many plans use a system of triggers to guard against overutilization of services. The continued need for a particular service is reviewed after a member receives a certain quantity of the service—for example, five days in a crisis facility. In some cases, additional services may be pre-authorized. While it may be appropriate for a plan to use triggers, their use should be carefully monitored to ensure that they do not become de facto pre-set limits on care.

To protect against arbitrary limits states should make clear that:

(a) all services shall be provided in sufficient amount, duration and scope to reasonably achieve their purpose;

(b) services shall not be denied based on pre-set limits on the duration of services; instead, reviews of the continued need for services shall be conducted on an individualized basis;

(c) pre-authorization procedures are not de facto limits on duration of services;

(d) services may not be denied or reduced in scope based on an individual's diagnosis, type of illness or condition suffered, and

(e) services may not be denied pending appeal.

F. Process to Determine When Services Are Medically Necessary

The best definition of "medically necessary" will be of no avail if the managed care entity has established a system for determining necessity that results in inadequate or inappropriate implementation of the criteria.

Managed care plans may use a variety of methods to make determinations of medical necessity. Prior authorization for certain services, concurrent utilization reviews, centralized assessment and referral, gatekeeper screenings, case management and designated provider networks are all methods used by managed care plans to limit access to services. Errors in implementation of any of these mechanisms can deny consumer choice and access to services.

To guard against improper denials, states should establish standards in their contracts with managed care entities for the process by which medical-necessity determinations are made. For example, some managed care contracts require that personnel who make medical-necessity determinations have specific credentials. In addition, some states have enacted relevant statutes, which should be referenced in the contract.

At a minimum, states should include in the contract provisions the process that should be followed.

Medical necessity determinations shall be made in accordance with the following standards:

(a) decisions should initially be made by the Member and the Member's treating provider; however the plan may establish protocols for when further approval is necessary;

(b) when further approval is necessary, decisions shall be made in a timely fashion and the plan shall respond within ____ to pre-authorization requests;

(c) decisions shall be made by appropriately trained mental health professionals with sufficient clinical experience (including experience in treating adults with serious mental illness and children with serious emotional disturbance);

(d) the plan shall document how decisionmakers considered the recommendations regarding medically necessary services from the treating professionals as well as the desires of the Member and document specific reasons for overriding such recommendations and desires;

(e) determinations of medically necessary shall be based on practice guidelines (if the plan uses written practice guidelines), which shall be consistent with the provisions of Sections A-D;

(f) criteria for medically necessary services and any practice guidelines used are distributed to all providers who participate in the plan and, upon re-

quest, are available for review by plan Members; plan Members shall receive information describing the method for obtaining access to the criteria and guidelines.[19]

G. Link to an Appeal System

Regardless of how well the plan does, there will always be occasions of dispute between the plan and members about decisions on medical necessity. The contract should therefore clearly spell out an appropriate grievance and appeal mechanism, and the contract's definition of "medically necessary" should form the basis for resolving such disputes.

(a) decisions as to whether a particular service, supply or technique is medically necessary shall be subject to appeal by a Member under section ____ (appeal provisions); the definition of medical necessity set forth in ____ shall form the basis for resolving such disputes;

(b) Members may also use the grievance process set out in _____ (grievance process) to complain about medical necessity decisions. The definition of medical necessity set forth in Section _____ shall form the basis for resolving such grievances;

Sanctions

In developing contracts for managed mental health care, states will need to address the issue of what sanctions are applied should the plan fail to comply with the provisions of the contract. Unless specific sanctions apply if a plan violates the requirements of the medical-necessity criteria, the state will have only limited options: to ignore the violations, to pressure the plan to address the violations or to cancel the entire contract. A better approach would be to delineate specific interim sanctions, such as monetary penalties, for failure to follow the medical-necessity criteria appropriately.

Failure of a plan to deliver services according to the above criteria shall be cause for sanctions, as described in Section ____ of the contract.

CONCLUSION

The material in this document covers a significant range of issues, expanding the concept of medically necessary beyond the definitions in most current state contracts. It is intended to stimulate new thinking about decisionmaking regarding what services will be furnished to an individual under public-sector managed care plans, when and for how long. The elements discussed in sections (A) through (G) above should all be addressed. The language in this document is included as an example, and states may wish to adapt it to reflect their current state mental health policies and definitions or to fit the approach to managed mental health care being taken in the state.

The Center for Mental Health Services and the Bazelon Center for Mental Health Law are interested in receiving feedback on the concepts in this paper, and in assisting consumers, families and advocates in understanding and securing appropriate definitions of when a service will be considered medically necessary for adults with serious mental illness and children with serious emotional disorders.

Prepared by:
Chris Koyanagi
Ira Burnim
Joseph Bevilacqua
Michael Allen
Judge David L. Bazelon Center for Mental Health Law

NOTES

1. Throughout this paper reference is made to mental health services; however, these recommendations are equally applicable in concept to addiction services and could be adapted to address both mental health and substance abuse services (behavioral health services) in states that have managed care plans addressing both needs.
2. Public managed care arrangements can be set up at the state, local or regional level. For the sake of simplicity, the word "state" is used in this document to represent any government entity contracting for managed behavioral health care.
3. Utilization reviews evaluate the necessity and appropriateness and efficiency of ser-vices, such as reviewing appropriateness of admissions, services ordered and provided, length of stay on a concurrent or retrospective basis. Prior authorization is the approval a provider must obtain from a payor before furnishing certain services, used particularly for inpatient hospital care.
4. Under the U.S. Constitution, individuals have a right to mental health care when they are confined by the government, *Youngberg v. Romeo*, 457 U.S. 307 (1982), or when the government otherwise plays a dominant role in their lives, *Spivey v. Elliott*, 41 F.3d 1497 (11th Cir. 1995) ("the question is...the extent the State exercised dominion and control over that individual"). *See also Thomas S. v. Flaherty*, 902 F.2d 250 (4th Cir.), *cert. denied*, 498 U.S. 951 (1990);

Halderman v. Pennhurst State School and Hospital, 784 F. Supp. 215, 222-23 (E.D. Pa.), *aff'd*, 977 F. 2d 568 (3d Cir. 1992); *McNamara v. Dukakis*, 1990 WL 235439 (D.Mass. 1990). State constitutions and statutes may also create entitlements to mental health care.

5. 42 U.S.C. §§ 1396d(a)(6), 1396d(a)(11), 1396d(a)(13), 1396d(r)(5).

6. 42 C.F.R. § 440.230(d).

7. 42 C.F.R. § 440.230(b).

8. 42 C.F.R. § 440.230(c)(1). The U.S. Supreme Court has used a similar standard in defining the scope of the constitutional "right to treatment." *Youngberg v. Romeo*, 457 U.S. 307 (1982). See generally Stefan, *Leaving Civil Rights to the "Experts": From Deference to Abdication Under the Professional Judgment Standard*, 102 Yale L.J. 639 (1992).

9. The term medical-necessity is used in other related areas of law. For example, several courts have considered the meaning of "medical necessity" when it appears in private insurance contracts.

10. The judicial opinions cited here are binding only within the territory over which the deciding court has jurisdiction. However, these opinions are likely to influence other courts. In deciding a legal issue, courts review how other courts have handled the matter and often defer to the reasoning of the other court's decisions. Thus, the opinions cited in this section can be considered as guidance as states develop their policies for setting standards with regard to when a service is medically necessary.

11. 756 F. Supp. 501, 507 (D. Kan. 1990) (internal citations omitted).

12. 432 U.S. 438, 444 (1977).

13. 886 F.2d 194, 200 (8th Cir. 1989).

14. *Pinneke v. Preisser*, 623 F.2d 546, 550 (8th Cir. 1980). *See also* S. Rep. No. 404, 89th Cong., 1st Sess., *reprinted in* 1965 *U.S. Code Cong. & Admin. News* 1943, 1986, ("the physician is to be the key figure in determining utilization of health ser-vices").

15. 42 C.F.R. § 440.230(b).

16. *Medicaid Managed Mental Health Care: Survey of the States*, April 1996, Bazelon Center for Mental Health Law, Washington DC.

17. Medicaid Managed Mental Health Care: Survey of the States (II), March 1997, Bazelon Center for Mental Health Law, Washington DC.

18. Under Medicaid law, Medicaid, not the school system, must pay for covered ser-vices furnished to a child; even when these services have been found necessary and included in the child's IEP or IFSP. This language would ensure that the managed care plan assumes Medicaid's financial responsibilities in these circumstances.

19. This point may have to be argued, based on state law. Managed care entities will attempt to avoid releasing this information on the basis that it is proprietary. However, in a public program of benefits, all standards and criteria should be open to public scrutiny.

The Bazelon Center for Mental Health Law is the leading national legal-advocacy organization representing people with mental illness or mental retardation. Through precedent-setting litigation, public-policy advocacy and technical support for local lawyers and other advocates, the center works to define and uphold the rights of adults and children who rely on public ser-vices and ensure their equal access to health and mental health care, education, housing and employment. The Bazelon Center was founded as a nonprofit public-interest organization in 1972; its work is funded primarily by private foundations and individual donors.

BAZELON CENTER RESOURCES ON MANAGED BEHAVIORAL HEALTH CARE

The following materials are available from the Bazelon Center, as indicated below (prepaid by check, Visa or MasterCard; unless otherwise indicated, add $4 for postage and handling for orders under $15 and $1 more for each $10 above that):

- *Managing Managed Care for Publicly Financed Mental Health Services* (November 1995), $9.40
- *Managing Behavioral Health Care for Children & Youth: A Family Advocate's Guide* (August 1996), $9.95 in English or Spanish (single copy includes 16-page booklet for parents, *Your Family and Managed Care*, in the same language; booklet separately, $3.50)
- *Protecting Consumers in Managed Care: Resources for Legal Advocates* (June 1996), $5
- *Buying in the Public Interest: A Primer for Purchasers of Managed Behavioral Health Care in the Public Sector* (November 1996), $20
- *Can Managed Care Meet the Mental Health Needs of Very Young Children?* October 1996 issue paper), $3
- *Assessing Approaches to Medicaid Managed Behavioral Health Care*, on the use of carve-outs for managed mental health care, prepared for the Kaiser Commission on the Future of Medicaid (February 1997), $7 includes postage and handling
- *Mental Health Managed Care Survey of the States, 1996-97* (March 1997), $10 includes postage/handling
- Issue Paper #1: *Defining "Medically Necessary" Services to Protect Plan Members* (March 1997), $5 includes postage/handling
- Issue Paper #2: *NCQA Accreditation Standards: Insufficient Quality Check Unless Supplemented for Public-Sector Systems* (April 1997), $5
- Issue Paper #3: *An Evaluation of State EPSDT Screening Tools* (June 1997), $5
- Issue Paper #4: *Assessing Report Cards* (June 1997), $5
- *Successful Coalition Advocacy for State-Based Managed Care: A Case Example* (in preparation)
- *Consumer Rights in Managed Care* (in preparation)

Excerpts from some of these publications and announcements of new materials as they are developed can be found on the managed care page of the ~~Bazelon~~ Center's Internet site: http://www.bazelon.org.

To order publications, send check or Visa/MasterCard authorization to Publications Desk, Bazelon Center for Mental Health Law, 1101 15th Street NW, Suite 1212, Washington DC 20005; fax: 202-223-0409.

MANAGED CARE & VULNERABLE AMERICANS

Children With Special Health Care Needs

July 1997

Providing care to more than 10 million children with special health needs poses some of the most difficult, complex, frustrating and costly challenges for their families, their schools, social service programs — and the health system. These children require care over a long period of time that can be as simple as speech and physical therapy or as complex as home management for a child needing a respirator to breathe.

The goal in providing appropriate treatment for these children is not simply to stabilize or shore up the effects of their immediate medical conditions, but to use pediatric health services in a combination of settings to help them develop to their fullest potential in a cost-effective manner. Costs can vary considerably, with a handful of children requiring the vast majority of services each year. For example, the average cost to Medicaid of caring for a child with diabetes is $2,300 a year — but exceeds $370,000 for a few.

As with most Americans, children with special needs are today facing a retooled health care marketplace governed by the principles of managed care. Whether covered by private insurance plans or public health programs — and many receive assistance from both — managed care in the future may well dictate the location, quantity and quality of services for these children. But before managed care is embraced as the coverage of choice for children with special needs, state and federal policy makers, as well as employers, must address a number of key issues. Ultimately, they must decide whether care can be managed to improve quality and coordination for children with special health needs—and achieve savings.

KEY DATA

10.5 million to 12.6 million children with special health care needs (15% to 18%) in 1994-95

955,000 children with disabilities receiving Supplemental Security Income (SSI) that qualified them for Medicaid in 1996 (as many as 30,000 could lose Medicaid coverage due to welfare reforms)

$7,128 average per capita Medicaid spending for kids on SSI in 1995

$920 average per capita Medicaid spending for all kids in 1996

1.4 million children with special health needs are uninsured

36% with special health needs discharged from children's hospitals assisted by Medicaid in 1996

40% with special health needs discharged from children's hospitals assisted by private insurance in 1996

36 states mandating managed care arrangements for at least some children with special needs

KIDS WITH SPECIAL NEEDS

Estimates of the number of children with special health needs vary depending on medical conditions and other factors included in the definition. Some studies that include a broad range of conditions, such as recurrent ear infections and headaches, have found that one of every three children, or 23 million, have special needs. The most widely accepted study for this report's purpose puts the number at 15% to 18%, or 10.5 million to 12.6 million.[1]

Many health conditions require children and their families to seek medical and other support services over a long course of time. Most are rare, but collectively significant. The most prevalent chronic conditions affecting children include asthma, and attention deficit and disruptive behavior disorders. Other less prevalent conditions include diabetes, sickle cell anemia, cystic fibrosis, spina bifida, cerebral palsy or mental impairments. They can be children with unstable or deteriorating conditions, such as muscular dystrophy or HIV infection. Some have congenital anomalies, such as cleft palate, or are born with problems making it difficult to digest or metabolize food. Often a child has more than one condition.

Some of these infants, children and adolescents may have trouble participating in school or play. Others need a range of therapies and special treatments, while still others are dependent on life-sustaining medications or diets, or use of such devices as wheel chairs, prostheses or hearing aids. Most need ongoing medications, self and family case management and intermittent mental health care and family support.

Alliance for Health Reform, 1900 L Street N.W., Suite 512, Washington, D.C. 20036
Phone 202/466-5626, Fax 202/466-6525

Supported by a grant from the Robert Wood Johnson Foundation

ALLIANCE
FOR
HEALTH REFORM

[redacted]

THE VARIABILITY OF SPENDING

Medical conditions affecting children with special needs—and the resulting costs of their care—vary enormously.

For example, a soon-to-be published article in *Pediatrics* (Ireys, Anderson Shaffer & Neff) shows that in 1993 Washington state's Medicaid program spent *on average* —

- **$14,377 for a child with cystic fibrosis**
- **$16,684 for a child with muscular dystrophy**
- **$14,637 for a child with a malignant neoplasm**
- **$2,584 for a child with asthma**

The total spending for all children in the state provide a different picture —

- **$37 million for all children with asthma**
- **$8.4 million for all children with malignant neoplasms**
- **$2.9 million for all children with cystic fibrosis**
- **$2.8 million for all children with cerebral palsy**

Thus the condition least expensive to treat—asthma—costs the program far more than more expensive, but far rarer, conditions.

Children with special needs are more likely than healthy children to be living in households with lower incomes and with adults who have less education. They are half again more likely to live at or below poverty, and thus depend on Medicaid. Chronic childhood conditions increase with age and affect males more than females. White and African American children are more often reported to have special health needs than Latino or other racial and ethnic groups.

THE COST OF CARE

There are no current reliable national estimates on the cost of caring for children with special needs. But Medicaid data provide some glimpse of what it costs to serve children with disabilities. Disabled children on Medicaid, with incomes low enough to qualify for Supplemental Security Income (SSI), are more likely to have severe, higher cost conditions than others with special needs. In 1995, state and federal governments contributed through Medicaid $6.8 billion, or $7,128 on average for each of 955,000 disabled children. The average for all children on Medicaid in 1996 was about $920. (See box "The Variability of Spending.")

The most consistently expensive children are those who require institutional care or have long-standing dependency on such expensive technologies as respirators. For non-institutionalized children, much of the cost is driven by hospital stays. These children are nearly 4 times more likely to be hospitalized, have longer stays and see a physician three times more often than healthy kids. Those with physical health conditions are more than twice as likely to have secondary mental health problems.

The out-of-pocket expenses of families who care for children with special needs are not well documented. Nor are there good data on how family responsibilities in caring for these children affect parents' employment, or their physical and mental health. But families report that all these may be areas of stress, producing additional personal and financial costs.

Health plan limits on services covered may put the most direct financial stress on families. Plans increasingly restrict the number of services or types of benefits they cover. For example, a plan may limit the number of mental health or physical therapy sessions or may cover home care for only short periods. Plans may also be slow to cover the use of new technologies and therapeutic interventions.

WHO PAYS?

Financing the care of special needs children is considerably fragmented, and national data are unavailable to show the number in private plans, Medicaid and other public health programs — much less in managed care arrangements funded by either the public or private sector.

We do know that 1.4 million children with special health needs are uninsured. In addition, we know from a survey of inpatient discharges from 49 children's hospitals (see Figure 1) that —

- 36% of children with special health needs were assisted by Medicaid; and
- 40% had private insurance.[2]

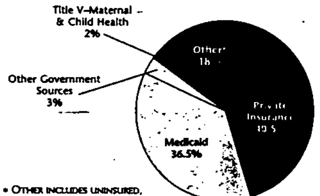
A Census Bureau survey from 1993-94 shows that 32% with disabilities under age 21 were on Medicaid.[3] Children can receive Medicaid benefits if their disabilities and family income qualify them for Supplemental Security Income (SSI), if family incomes are low enough, or if they meet other requirements that vary from state to state. As many as 30,000 children may lose Medicaid coverage, because of changes the 1996 welfare reform law made to SSI's definition of disability.

In many cases, privately insured children can receive additional assistance from publicly funded programs, even Medicaid, to cover what the private plan does not. (See box "EPSDT — The Debate.") In addition, all special needs children have access to some resources to help manage some of their health and education needs, including assistance from the federally funded but state-operated maternal and child health block grants. This aid varies from state to state but can include direct provision of medical care.

There are also a number of state and federal programs that provide early intervention to help children overcome develop-

Figure 1

THE PAYERS



* OTHER INCLUDES UNINSURED, MANAGED CARE CASES, MEDICARE, WORKERS' COMPENSATION AND MORE.

For children's hospital discharges only, see end note 2.

mental problems. In addition, federal law entitles children to receive special health-related services in schools to help educate them in the least restrictive environment. New legislation also allows schools to look to Medicaid to pay for health services provided in educational settings to special needs kids eligible for the program's coverage. This, in part, addresses the ongoing problem of cost-shifting among programs that may be exacerbated with the influx of private managed care plans.

A child with developmental disabilities may also look to the state-operated mental health system for such help as psychotherapy and family counseling. School systems offer programs for kids with special needs, and special diets are sometimes supported through the Special Supplemental Food Program for Women, Infants and Children. A wide array of private agencies also provide diverse types of assistance and family support. However, thousands of families in every state do not qualify for such assistance.

WHO CARES FOR THE KIDS?

All children need regular checkups, screening and preventive care. Special needs kids require much more. They may need evaluation and management by pediatric subspecialists expert in identifying medical conditions and their appropriate treatment. This may mean medical and surgical interventions, as well as such special care as renal dialysis or speech, physical and occupational therapies. Some children require home nursing and respiratory therapy, respite care or expensive appliances that need replacement as the child grows.

Although private and public insurance may cover some costs, families of all income levels face an extremely fragmented mix of agencies in the health, mental health, education and human services systems, all presumably designed to assist in meeting a child's multiple care demands. But public programs lack consistent eligibility and application procedures. Each agency may provide its own assessment and care plan, and perhaps its own case coordinator.

The frequent duplication and gaps in coverage pose formidable barriers to comprehensive and coordinated care and often require a huge investment of time and energy, draining family resources and interfering with parents' jobs. Families may find themselves locked into employment for fear that changing jobs would mean loss of access to those providers. Data clearly show that continuity and close partnership between a family and providers make it less likely that a person with disabilities will be placed in expensive institutions.

MANAGED CARE

Managed care differs from personal indemnity insurance in ways that may offer benefits and liabilities to children with special needs.

Managed care can —

- **Link the child with a primary care provider** who will coordinate the full spectrum of needed care.
- **Emphasize prevention** that can avoid costly hospitalizations.
- **Create flexible packages** of care that deliver services in the most cost-effective settings.

But moving children with special needs to managed care plans can potentially cause harm by —

- **Limiting children's access to pediatric specialists** and services. (Specialty centers have produced most of the new knowledge for conquering many childhood illnesses.)
- **Increasing the cost-shifting problem** already apparent, particularly between the education system and public and private health plans. As budgets shrink, cost shifting can ultimately target families.
- **Not adjusting payments enough** to reward plans that enroll and do a good job serving these higher cost children.

Indeed, with the incentives in the marketplace today, managed care plans are not eager to enroll special needs children, nor are families eager to see them enrolled. While these children require more services than the average healthy child, capitated private-sector and Medicaid managed care plans often receive the same premium for a sick child as for a healthy one, putting plans at greater financial risk if they reach out to enroll these children.

Nonetheless, 36 states have begun to mandate enrollment of at least some of these children. Few managed care contracts, however, include all standard Medicaid benefits for children. Thus, states must provide alternative ways of providing what plans exclude. This added complication can curtail access to services.

POLICY ISSUES

Managed care's focus on curtailing costs for three-quarters of the under-65 population has made it appealing to policy makers looking at ways to control costs of any local, state or federal program with "health" in the title. As lawmakers begin to discuss the best rubric to care for these most vulnerable children, they should address a number of issues.

EPSDT– THE DEBATE

A CORNERSTONE of the broad benefits children can receive if enrolled in Medicaid is known as the Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT). It's a program at the center of an important Congressional debate.

UNDER EPSDT, Medicaid must pay for any services needed to treat *or prevent* conditions in a child — not just services that treat a specific diagnosis, regardless of whether the service is in the state plan. This child-specific standard covers as "medically necessary" a range of therapies to improve function and prevent deterioration, such as speech, physical and occupational therapies — services that may not be covered by Medicaid for adults or offered in commercial plans. Finally, the EPSDT standard assures that non-health services needed to assure a child receives treatment are available. That may include translation, outreach and transportation.

THE BROAD SERVICE PACKAGE is designed to help prevent the development of expensive long-term medical problems and disabilities.

THERE IS CONSIDERABLE CONTROVERSY, however, about whether this child-specific standard of medical necessity should be maintained. Opponents argue that since private insurers do not guarantee such coverage, public programs should not either. They see the extra benefits as unnecessary. Proponents contend it is cheaper in the long run to provide preventive services that can enhance a child's development. Moreover, they argue children covered by EPSDT already face two strikes — they are poor, and they have complex health conditions.

What are the essential benefits and categories of services that children with special needs depend on? Are managed care plans organized to provide those benefits? Or should some services be "carved out" and provided by specialized or fee-for-service plans expert in areas not traditionally handled well by managed care, such as mental health, transportation, home and respite care, special education and nursing home care?

If states enroll special needs kids in managed care, should they negotiate with a plan that offers an organization designed to provide broad access to pediatric specialists, rather than mainstreaming them into plans that serve a broader population?

What is the best means to reward plans that enroll special needs children? Should capitated rates be adjusted upward to reflect the higher costs—and if they should, do we have the knowledge to adjust them wisely? Should states develop a reinsurance pool to protect plans from excessive losses?

Current pediatric quality measures focus on primary and preventive care, such as immunization rates and well-child visits. There are few measures for kids with chronic conditions. What measures should be used to assure these children receive appropriate care, and what public or private agency should develop the standard? What other protections — an appeals process or right to pediatric specialists, for example — should be considered?

Can managed care realize its potential to enhance the quality and improve the coordination of the complex care of children with special health needs — and achieve savings for all the public and private health and education programs involved in providing the care?

CONCLUSION

Children with special health needs could benefit from the coordination and management of care offered in a managed care environment. But the complexity of their needs makes the risks high as well — for families and for the plans. While managed care has fundamentally changed the health care marketplace, policy makers, employers and plans should all move with caution and sensitivity when eyeing these children with special health needs as managed care's newest clients.

END NOTES

1. Based on data from Phase I of the Disability Survey conducted by the National Center for Health Statistics as part of its 1994-95 National Health Interview Survey.
2. From the National Association of Children's Hospitals and Related Institutions 1996 Case Mix Database.
3. The Census Bureau defines disability as "difficulty in performing one or more functional or daily living activities, or one or more socially defined roles or tasks. Persons who are completely unable to perform an activity or task, or who must have personal assistance are considered to have severe disability."

ACKNOWLEDGMENTS

This publication was made possible by a grant from the Robert Wood Johnson Foundation. We are particularly grateful for the advice and support of Judy Whang and Marc Kaplan.

The Alliance would also like to thank pediatrician Ruth E.K. Stein, M.D., of the Albert Einstein College of Medicine whose research and policy analysis formed much of the basis for this paper. Thanks also to Judy Feder of Georgetown University's Institute for Health Care Research and Policy and Alliance interns David Mathison and Cara Andolina.

The Alliance is a bipartisan, not-for-profit group committed to the education of journalists, elected officials and other shapers of public opinion in helping them better understand the roots of the nation's health problems and the trade-offs posed by various reform proposals. The Alliance was founded in 1991 to help provide opinion leaders an objective source of information on those problems and proposed solutions.

Design by Pensare Design Group Ltd.

REPRINTS

An additional copy of this paper can be obtained by sending a self-addressed #10 envelope with 32¢ postage to:

Alliance for Health Reform
1900 L Street, NW, Suite 512
Washington, DC 20036

For multiple copies:
Telephone 202/466-5626
Fax 202/466-6525

FOR MORE INFORMATION,

Polly Arango, *Family Voices*	505/867-2368
Carmella Bocchino, *American Association of Health Plans*	202/778-3278
Harriet Kohen, *Center for Children with Chronic Illness & Disability, University of Minnesota*	612/6264032
Patrick Chaulk, *Annie E. Casey Foundation*	410/223-2980
Bob Cole, *Washington Business Group on Health*	202/408-9320
Margot Edmunds, *Institute of Medicine*	202/334-2184
Harriette B. Fox, *Health Policy Consultants*	202/223-1500
Henry Ireys, *Johns Hopkins University*	410/550-5442
Jane Koppelman, *National Health Policy Forum*	202/872-0239
Richard Kronick, *University of California School of Medicine, San Diego*	619/534-4273
Margaret A. McManus, *McManus Health Policy Inc.*	202/686-4797
Merle McPherson, *Maternal and Child Health Bureau Department of Health and Human Services*	301/443-2350
Paul Newacheck, *University of California at San Francisco*	415/476-3896
Jackie Noyes, *American Academy of Pediatrics*	202/347-8600
James Perrin, *Massachusetts General Hospital/ Harvard Medical School*	617/726-8716
Sara Rosenbaum, *Center for Health Policy Research George Washington University Medical Center*	202/530-2343
Stephen Somers, *Center for Health Care Strategies*	609/279-6700
Ruth E.K. Stein, *Albert Einstein College of Medicine*	718/918-5304
Sallie Strang, *National Association of Children's Hospitals & Related Institutions*	703/684-1355
Mary Tierney, *Health Services for Children with Special Needs*	202/466-7474
Myrl Weinberg, *National Health Council*	202/785-3910

BAZELON
CENTER
MENTAL
HEALTH
LAW

Protecting Consumer Rights in Public Systems' MANAGED MENTAL HEALTH CARE POLICY

A Series of Issue Papers on Contracting for Managed Behavioral Health Care

#2

NCQA ACCREDITATION STANDARDS: *Insufficient Quality Check Unless Supplemented for Public-Sector Systems*.

The National Committee for Quality Assurance (NCQA) recently released standards for accreditation of managed behavioral healthcare organizations. NCQA has previously provided accreditation for managed *health* care plans (such as health maintenance organizations); the new standards will result in NCQA's accrediting managed *behavioral* health care plans as well, such as those now contracting with states to manage public mental health and addiction treatment systems.

The new NCQA behavioral health care standards are not specifically designed for public-sector managed care. The Bazelon Center for Mental Health Law considers them to be insufficient as a quality control for mental health and addiction services funded by Medicaid or mental health, substance abuse or other public agencies. The standards may be more appropriate for use by plans contracting with a business for an acute-care behavioral health benefit for its employees.

To ensure appropriate quality and performance standards in public-sector contracts with managed behavioral health care entities, public purchasers (states or local governments) should address various issues more comprehensively than does NCQA. In this analysis, the Bazelon Center identifies areas in which public purchasers should expand their standards for managed care entities beyond the NCQA minimum.

OVERVIEW OF STANDARDS

The purpose of establishing accreditation standards is to set a minimum level of quality control over health care providers or managed care entities. In addition to NCQA, other entities (such as the Joint Commission on the Accreditation of Healthcare Organizations) issue proposed standards or accredit mental health agencies. By providing this analysis of the NCQA standards, the Bazelon Center does not intend to endorse the use of any particular accreditation process.

The NCQA Standards for Accreditation of Managed Behavioral Healthcare Organizations encompass standards for:

- Quality Management and Improvement (Standards QI 1 to QI 11)
- Accessibility, Availability, Referral and Triage (Standards AR 1 to AR 4)
- Utilization Management (Standards UM 1 to UM 9)
- Credentialing and Recredentialing (Standards CR 1 to CR 13)
- Members' Rights and Responsibilities (RR 1 to RR 8)
- Preventive Behavioral Health Services (Standards PH 1 to PH 4)
- Clinical Evaluation and Treatment Records Standards TR 1 to TR 3)

WHAT PUBLIC PURCHASERS CAN DO

In making the move to managed care, states and other public purchasers should review various proposed standards for managed care entities serving the public sector and make their own decisions about which to accept or adapt to their particular circumstances. One approach would be to draw from the state system's existing standards.

While declining to endorse any entity's specific accreditation standards, the Bazelon Center does recommend that purchasers who elect to use the NCQA standards as a base strengthen them in certain critical areas, listed below. Many public purchasers may well wish to go further.

Overview

The NCQA standards have the following general shortcomings with respect to issues of importance to public-sector mental health and addiction service delivery:

Consumer Involvement

There are no standards for member involvement in the critical decisions made by the plan (i.e., no requirements for consumer participation on advisory committees or governing bodies). Further, while the final standards are an improvement over a draft released for comment in 1996, the requirements for members to be involved in various aspects of the plan, or to receive information on critical aspects, are minimal.

Public Information

A contract to provide public-sector services must operate in a far more open way than a contract with an employer. NCQA fails to address this issue and omits requirements for public release of key information, such as utilization-management procedures, data on grievances and appeals, and outcome measurements.

Continuity

Adults with serious mental illness and children with serious emotional disturbance require services from multiple public agencies and will continue to do so under managed care arrangements. NCQA does not have adequate standards regarding linkages and collaboration between managed care plans and other state systems serving the same individuals.

Special Populations

A number of special populations who rely on the public sector have needs that are especially challenging. These groups include people who live in rural areas or are homeless, elderly or dually diagnosed with mental retardation and mental illness or with substance abuse and mental illness. Since public contracts for managed care represent their safety net for behavioral health care, special attention is required to ensure that needs particular to each of population are addressed. NCQA does not include adequate standards for outreach and other specific interventions for special populations; the NCQA standards will not, therefore, enable purchasers to determine whether plans are meeting their needs.

Children

Children's needs are different from adults'. The types of services children receive, the way services are delivered to children and their families, and the various developmental stages of children present different challenges to managed care entities. In addition to lacking any section on children's issues, the NCQA standards rarely mention children's particular needs or address children's service delivery specifically. While the standards are intended to be generic, it is more accurate to characterize them as adult-focused.

Notification of Potential Threats to Safety

NCQA's own policies and procedures include a provision that NCQA will notify the managed care plan's CEO when it identifies a deficiency in the plan's operations that "poses a threat to public health or safety, or to the health or safety of members" (page 20 of Policies and

Procedures section). Public payors should require that NCQA also inform them in such circumstances.

Corrective Actions

NCQA's requirements for corrective action generally suggest that the plan take action. In order to better protect plan members from inadequate or abusive care, public payors should consider mandating specific corrective actions for specific circumstances.

Delegation

Throughout the standards are requirements regarding the delegation of activities and responsibilities to other entities or to network providers. In none of these instances does NCQA require that the subcontract between the managed care entity and the other organization be made available to the public payor and the public. Yet, in the case of a public system, these are contracts for public services and should be open to public scrutiny.

Focus on Process

The standards are very process-oriented, requiring the tracking of various processes and activities within a managed care plan. However, there is very little emphasis on true measures of quality of care, such as health and mental health outcomes for the members served by the plan.

ASSESSMENT OF STANDARDS

In addition to these overall concerns, the Bazelon Center has identified specific additional requirements that should be considered by public purchasers. This section-by-section analysis highlights the problem areas in the NCQA standards. ~~Ho~~wever, it does not suggest alternative or additional standards. Other resources to guide that complex process are suggested at the end of this paper.

Quality Management and Improvement (Standards QI 1 to QI 11)

a) Member Satisfaction (QI 4):

NCQA relies on consumer-satisfaction surveys. However, accurate assessment of member satisfaction and of the problems members have with their plan requires more than consumer-satisfaction surveys, which traditionally produce generalized high ratings but fail to uncover specific information or problems. Purchasers might consider using focus groups, ombudsman programs, hot lines, sample interviews conducted by consumers, families or advocates, etc.

Although stakeholders should have access to such important data, NCQA has no standard for making results of member-satisfaction assessments public.

b) Clinical Practice Guidelines (QI 5)

The use of clinical guidelines should not result in arbitrary decisions about service options which ignore the member's wishes. Managed care plans should meet the individual needs and preferences of members. The NCQA standards on clinical practice guidelines fail to address this issue.

c) Continuity and Coordination of Care (QI 6)

For adults with serious mental illness and children with serious emotional disturbance, managed behavioral health care plans must be linked with the various support services provided through other public agencies. In the standards on continuity and coordination of care, NCQA addresses only the need for coordination with general medical care.

d) Scope and Content of Clinical QI Activities (QI 7)

NCQA lays out minimum requirements with respect to the relevant clinical issues that a plan must assess as part of its quality-improvement activities. NCQA requires only that three clinical issues be identified for assessment and evaluation (reduced from five clinical issues in an earlier NCQA draft). Further, this section of the standards has no focus on outcome. Public payors will wish to be explicit about which clinical issues are selected as measures of plan performance and to focus on issues relevant to the population covered under the public-sector managed care plan. They will also wish to emphasize outcomes as well as performance criteria.

e) Intervention and Follow-Up (QI 9)

NCQA requires that managed care entities identify opportunities for improvement and take action to improve performance regarding specific practitioner or provider performance issues as well as system-wide issues. Establishing the details of how system-wide issues are to be identified and corrected is an important area for public payors, which the standards do not attempt to address.

f) Program Effectiveness (QI 10)

NCQA fails to require that information from the plan's assessment of its overall effectiveness be shared on a regular basis with the public payor and made available to the public.

Accessibility, Availability, Referral and Triage

a) Accessibility of Services (AR 1)

The standards regarding accessibility are very limited and generally do not address accessibility issues as understood in the public sector. NCQA standards focus on measures of availability suitable for a working population (e.g., how quickly telephone queries are answered and whether members get appointments when they should). While these are useful, public payors will want to consider issues such as outreach, services to homeless persons, cultural barriers to access, language barriers, the need for assertive follow-up for members who have not kept appointments, etc. Public purchasers should consider setting their own detailed standards regarding the availability and effectiveness of critical services for special populations.

NCQA does not require the information collected about plan performance on measures of access to be made available to the payor or to the public. However, stakeholders should have the opportunity to review how well a plan is doing in reaching the covered population, including hard-to-serve groups.

b) Referral and Triage (AR 3)

In public-sector systems, referral and triage should include consideration of the need for various services furnished through various systems, such as health care, social services, housing and education. The NCQA standards address only referral to behavioral health services within the managed care plan and do not address the need for referrals to external agencies and programs providing related services. A definition of what is meant by referral and triage would be beneficial, along with specific standards with respect to referral for various support services.

Utilization Management

a) Utilization Management (UM 1)

NCQA requires that there be a written description of the utilization-management program outlining its structure and accountability. This description should be made available to the public payor and the public.

b) Utilization-Review Criteria

Utilization-management standards are required to be based on "reasonable scientific evidence." However, it is also appropriate and, in the public sector, often necessary that services be provided if they are considered "best practice." Waiting for the publication of "reasonable scientific evidence" can stifle the service system's capacity to provide the most promising interventions.

NCQA does not require utilization-management criteria to be made available to the payor or to the public, yet these criteria will determine what services are provided to members, under what circumstances and for how long.

c) Timeliness of Utilization Management Decisions (UM 4)

NCQA requires that the plan establish standards for timeliness of its utilization-management decisionmaking. In the case of public systems, the payor may wish to establish its own requirements as to what those standards should be in (1) emergency, (2) urgent and (3) routine situations.

d) Medical Necessity (UM 5)

NCQA requires that the plan "consult" with the treating professional. However, the role of treating professionals and the weight to be accorded their recommendations should be more clearly spelled out.

NCQA makes no references to the member's choice. Yet in determining whether a service is necessary, a member's preferences should be taken into account. This is particularly true if the member has rejected one form of treatment but seeks an alternative that is also an effective intervention.

NCQA appropriately makes no specifications in the accreditation standards regarding what is an acceptable definition of medical necessity. Public purchasers should insist on creating this standard themselves.

For more information on decisionmaking regarding when a service is medically necessary, see the Bazelon Center issue paper, Defining "Medically Necessary" Services to Protect Plan Members *(see resource list).*

e) Utilization-Management System: Incentives

NCQA standards do not address several areas of concern regarding managed care plans' relationships with providers in their network, through which the plans may encourage, or even force, practitioners to deny appropriate care. Standards should be established in public-sector contracts so as to prohibit plans from paying bonuses or imposing penalties on providers based on provider treatment recommendations and to specifically forbid the inclusion of "gag rules" that prevent providers from communicating their own recommendations for treatment to their patients.

f) Use of New Technologies (UM 7)

NCQA requires the managed care organization to evaluate new clinical technologies and new applications of existing technologies for potential inclusion in the benefit package. However, in public-sector mental health care, new *service* technologies (as well as new "clinical" technologies) should be considered.

NCQA has no requirement that members, consumer representatives or advocates be given the opportunity for input on decisions regarding the use of new technologies. Yet such individuals could play an important role in bringing new services to the plan's notice and assessing whether members would be likely to find a new service helpful.

g) Member and Practitioner Satisfaction with UM Process (UM 8)

NCQA requires plans to gather information from members and practitioners regarding their satisfaction with the UM process at least every two years. This is a very long time for members and practitioners to remain dissatisfied. A requirement to gather *and assess* information from members and practitioners at least once a year would result in a smoother-working system.

— *Credentialing and Recredentialing*

a) Non-Traditional Providers

NCQA credentialing standards assume that a network of mental health professionals is providing care in traditional settings. Strong public-sector systems, however, include a variety of alternative programs and agencies and utilize a range of individuals to furnish services, including consumers and family groups. Public-sector services must also take account of the variety in the types of providers working in different systems, such as schools and child welfare service providers.

The NCQA approach to credentialing standards can also hamper the provision of comprehensive coordinated care through community agencies, by forcing managed care plans to operate through the individual practitioners who work in such agencies, instead of contracting with the agency itself as a provider, except in limited circumstances (see CR 12 below). This can have an adverse impact both on the agency, which must bill in more complex ways, and for plan members, who may not have access to some of the agency's services.

Public purchasers should include in contracts specific provisions that override the limited NCQA credentialing process and replace it with standards tailored to the state's system.

b) Written Policies and Procedures (CR 1)

The NCQA standards reference specialists "registered by the state." Public payors may wish to use this standard in order to build a complete list of the programs and traditional and non-traditional providers with whom the plan is expected to contract. Otherwise, the NCQA standards on credentialing may prove a barrier to good care in the public sector (see above).

c) Credentialing Committee

Credentialing committees should include representatives of all peer groups, including non-traditional providers. Public payors may also wish to require inclusion of representatives of plan members, family groups or advocacy organizations on such committees, at least in an advisory capacity.

d) Credentialing Process (CR 3, CR 4, CR 5)

All of these standards regarding credentialing will need to be strengthened in order to accommodate appropriately the need for non-traditional providers.

e) Organizational Providers (CR 12)

NCQA includes a category of organizational providers with whom a managed care entity can contract for all of the organization's costs in providing services. However, the NCQA standards' examples of organizational providers is narrow. Public payors should consider expanding the list to include all appropriate community-based agencies and providers from other systems (schools, etc.) as appropriate.

Standards for Members' Rights and Responsibilities

a) Members' Rights (RR 1)

NCQA's statement of rights is minimalist and does not include the range of rights issues normally addressed in public mental health systems. Important rights, well-established in law, are omitted, such as the right to receive services free from discrimination based on race, gender, age, national origin or disability; the right to give informed consent, the right to refuse treatment, the right of access, the right to adequate care and treatment, the right to review records, the right to execute advance directives, and the right to be treated with respect.

Other rights recognized in mental health care settings are also missing. The right to an individualized plan of care and to be a partner in treatment planning, the right to care in the least restrictive setting, the right to a second opinion and the right to change providers are not referenced.

For additional information on individual rights under managed behavioral health care plans, see the Bazelon Center issue paper on rights (listed in resource attachment).

b) Information on Rights

Standards for distribution of information to members concerning their rights require only that the plan "distribute" the organization's policy. Entirely missing are requirements on how that should be done. Public purchasers will want to require plans to ensure that all members fully understand their rights and have ready access to this information when they are concerned that their rights may be being violated. Rights statements, for example, could be required to be distributed in all provider offices and mailed annually with plan information.

c) Member Responsibilities (RR 1)

NCQA's listing of member responsibilities is extremely problematic, and it is unclear what happens if a member fails to carry out these "responsibilities." Most public systems do not take this approach to provision of mental health care and some of the NCQA standards need to be overridden for an effective public system. Especially problematic is the standard that members must follow plans and instructions for care. Member non-compliance with treatment plans may be reflective of poor treatment plans and lack of provider responsiveness. Attempting to compel members' compliance through accreditation standards is unacceptable. States should ensure that no managed care plan can disenroll a member for failure to "follow plans and instructions for care" even when the member has participated in treatment planning.

d) Complaints and Grievance Systems (RR 3, RR 4)

The NCQA standards on complaints and grievances provide a broad outline of an appeals process. However, much more detail will be necessary for public systems, such as what can be appealed, the standard for review, criteria to be used by the review panel, member input into the grievance policies and procedures, member involvement in facilitating resolution of grievances, specific timelines for resolution of complaints, continuation of services pending appeal and other issues.

The Bazelon Center is preparing an issue paper on grievance and appeals, to be available in summer 1997.

e) Information for Members (RR 5, RR 6)

Standards regarding information to members overlook problems many public-sector clients may encounter. Information should be more accessible (in Braille and on audiotape, in all appropriate languages) and more readily available (provided in various settings at various times).

Plans should also be required to distribute information on a wider range of issues, particularly on utilization-review procedures.

For more suggestions on information distribution, see Managing Managed Care *from the Bazelon Center (see resource list).*

f) Care of Minors and Adults Adjudicated Incompetent (RR 7)

NCQA standards on these issues, which are of major importance in public systems, is totally inadequate and merely requires managed care plans to develop their own policies. Public payors should ensure that managed care plans follow appropriate laws so that adults exercise their own rights, unless adjudicated incompetent in court, and that they have the right to develop advance directives and proxies. Rights for minors should include appropriate standards for older adolescents to exercise certain rights on their own behalf.

g) Confidentiality (RR 7)

NCQA standards on confidentiality require that managed care plans, policies and procedures conform to all federal and state confidentiality regulations. Public payors that wish to address other issues will need to augment the NCQA requirements.

Areas that might be added to the NCQA standards include the need for regular training of plan providers and staff concerning confidentiality issues, especially as new technologies and systems come on line, and the special confidentiality questions that arise when dealing with public-sector issues, such as in instances of abuse investigations.

Preventive Behavioral Health Services

a) Preventive Programs (PH 1 to PH 4)

The NCQA emphasis on preventive services provides a base on which public payors could build more substantial requirements. For example, payors could require identification of known risk factors (such as young children whose parents have a mental illness or addiction disorder) and require effective screening programs *(see Bazelon Center issue paper in resource list)* and development of specific interventions for these high-risk populations. Appropriate integration of behavioral health issues in primary care for very young children might also be addressed.

NCQA allows the organization to select at least two preventive screening and educational interventions for monitoring and evaluating. Public payors may wish to be specific on what is required under this standard and may also wish to require that more than two interventions be monitored. (PH 4)

Clinical Evaluation and Treatment Records

a) Access to Records

Public agencies typically give individuals appropriate access to their records and the opportunity to correct errors in the record. Standards regarding access should be added to the NCQA requirements on treatment records.

BAZELON CENTER RESOURCES ON MANAGED BEHAVIORAL HEALTH CARE

The following materials are available from the Bazelon Center, as indicated below (prepaid by check, Visa or MasterCard; unless otherwise indicated, add $4 for postage and handling for orders under $15 and $1 more for each $10 above that):

◆ *Managing Managed Care for Publicly Financed Mental Health Services* (November 1995), $9.40

◆ *Managing Behavioral Health Care for Children & Youth: A Family Advocate's Guide* (August 1996), $9.95 in English or Spanish (single copy includes 16-page booklet for parents, *Your Family and Managed Care*, in the same language; booklet separately, $3.50)

◆ *Protecting Consumers in Managed Care: Resources for Legal Advocates* (June 1996), $5

◆ *Buying in the Public Interest: A Primer for Purchasers of Managed Behavioral Health Care in the Public Sector* (November 1996), $20

◆ *Can Managed Care Meet the Mental Health Needs of Very Young Children?* October 1996 issue paper), $3

◆ *Assessing Approaches to Medicaid Managed Behavioral Health Care*, on the use of carve-outs for managed mental health care, prepared for the Kaiser Commission on the Future of Medicaid (February 1997), $7 includes postage and handling

◆ *Mental Health Managed Care Survey of the States, 1996-97* (March 1997), $10 includes postage/handling

◆ Issue Paper #1: *Defining "Medically Necessary" Services to Protect Plan Members* (March 1997), $5 includes postage/handling

◆ Issue Paper #2: *NCQA Accreditation Standards: Insufficient Quality Check Unless Supplemented for Public-Sector Systems* (April 1997), $5

◆ Issue Paper #3: *An Evaluation of State EPSDT Screening Tools* (June 1997), $5

◆ Issue Paper #4: *Assessing Report Cards* (June 1997), $5

◆ *Successful Coalition Advocacy for State-Based Managed Care: A Case Example* (in preparation)

◆ *Consumer Rights in Managed Care* (in preparation)

Excerpts from some of these publications and announcements of new materials as they are developed can be found on the managed care page of the Bazelon Center's Internet site: http://www.bazelon.org.

To order publications, send check or Visa/MasterCard authorization to Publications Desk, Bazelon Center for Mental Health Law, 1101 15th Street NW, Suite 1212, Washington DC 20005; fax: 202-223-0409.

The New York Times

Home Sections Contents Search Forums Help

July 16, 1997

Governor Details Plan for *Managed* Health *Care*

By RAYMOND HERNANDEZ

ALBANY, N.Y. -- Gov. George Pataki unveiled his plan Tuesday to require most of the state's *Medicaid* recipients to join ***managed care*** programs, while exempting people in nursing homes, pregnant women and those living in areas with few ***managed-care*** companies.

The plan was released a day after the Clinton and Pataki administrations reached an agreement on a federal waiver to allow the state to phase out *Medicaid*'s traditional "fee for service" method of paying doctor and hospital bills.

The Clinton administration has already approved similar changes to ***Medicaid*** programs in at least 12 other states. But New York's plan would be the largest by far, with the state permitted to place 2.4 million of New York's 3.1 million ***Medicaid*** recipients into ***managed care*** programs in three years.

The plan would also exempt people with grave illnesses like AIDS until the state has developed a ***managed care*** plan that can deal with the complexities of their illnesses.

The governor has repeatedly promoted ***managed care*** as a way to save the state millions of dollars and improve health *care* for poor people, largely because ***managed care*** companies are paid a set rate for each patient and, in turn, seek to hold down costs by focusing on preventive medicine as well as limiting access to specialists. The traditional method, by contrast, generally pays doctors, hospitals and laboratories a separate fee for each medical procedure.

"We have been working hard at improving access to high quality medical ***care*** for the state's most needy citizens, and with this approval, we have taken a major step forward," the governor said.

The plan would phase recipients into ***managed care*** plans in stages: 945,000 in the first year; 1.6 million in the second year and 2.4 million in the third year. The administration estimates that the plan will reduce *Medicaid* spending by as much as $650 million once it is fully in place.

In a concession to hospitals and unions representing health ***care*** workers, who initially opposed the plan, it includes $1.25 billion in so-called transitional aid, federal money that is expected to come from savings in the new program. That money would allow public and nonprofit hospitals to operate community health clinics for *Medicaid* patients in poor areas traditionally underserved by doctors and medical centers.

The money would also be used for job training for hospital workers who might lose their jobs.

"Governor Pataki and his administration are to be congratulated for having the perseverance to continue to work for so long," Dennis Rivera, the president of 1199, the National Health and Human Service Employees Union, said during a news conference with the governor.

But some advocates for poor people continued to express concern that ***managed-care*** companies would not be able to absorb such a huge influx of new patients while still providing adequate ***care***. They noted that some companies had already begun to scale back their participation in an existing, voluntary ***Medicaid managed-care*** program, complaining that the reimbursement rates were too low.

Home | Sections | Contents | Search | Forums | Help

The New York Times

Home | Sections | Contents | Search | Forums | Help

July 16, 1997

The Odd Couple That Did the Heavy Lifting on Pataki's *Medicaid* Deal

By STEVEN GREENHOUSE

New York state officials from Gov. George Pataki on down took credit Tuesday for winning the Clinton administration's approval for a plan to enroll most of New York's 3.5 million *Medicaid* recipients in ***managed care***. But two men who are not on the state payroll did much of the hard work that clinched the deal.

Dennis Rivera, president of 1199, New York City's largest union of hospital workers, used his considerable influence in Democratic politics to press the federal government to block Pataki's *Medicaid* plan until it was changed to his liking, say officials involved in yearlong negotiations.

Kenneth Raske, executive director of the Greater New York Hospital Association, a group of 175 health ***care*** institutions, had the difficult task of lining up hospitals behind Pataki's plan.

It was Rivera who proposed that the federal government provide hundreds of millions of dollars to cushion New York's hospitals and hospital workers as they made the abrupt transition from ***Medicaid***'s fee-for-service payment system to ***managed care*** for ***Medicaid*** patients.

Under the plan announced Tuesday, New York state is to receive $250 million a year in federal money for five years to help hospitals and hospital workers as the health ***care*** industry in New York undergoes a major overhaul.

Rivera also brought Pataki together with Vice President Al Gore at last November's Al Smith political dinner at the Waldorf-Astoria to get them to cooperate on revising Pataki's plan to move most of the state's 3.5 million *Medicaid* recipients into ***managed care***. The plan required a federal waiver from ***Medicaid***'s fee-for-service payment system.

Raske, who said that his role was far less important than Rivera's, represented a constituency concerned about its ability to hold onto a large part of its patient base. Not being able to afford to build the walk-in clinics that many ***managed-care*** patients use, many hospitals feared that Pataki's plan would make them lose tens of thousands of lucrative ***Medicaid*** recipients once they joined ***managed-care*** plans.

"Without Ken, without his cooperation, this would have had a much more difficult time," said Jeffrey Sachs, an adviser to Rivera and a deputy health commissioner under Gov. Mario Cuomo. "He was able to bring the hospitals on board. They weren't necessarily in favor of the waiver."

Raske, who is on far better terms with Pataki than is Rivera, also served as an

Raske, who is on far better terms with Pataki than is Rivera, also served as an important go-between in shuttling information about Pataki's plans to Rivera and federal health officials.

Although the hospital association often clashes with Rivera's union, 1199, the National Health and Human Service Employees Union, Raske said, "If it wasn't for Dennis' persistence, this thing would have never happened."

Some political analysts say politics played a large part in Gore's decision to push for the ***Medicaid*** waiver and the transition money. Gore, they said, wanted to show some federal generosity to New York state to help position himself for the state's Democratic presidential primary in 2000.

Perhaps more important, these analysts said, Gore wanted to curry favor with Rivera, who is close to House minority leader Richard Gephardt, who is also expected to run in the 2000 Democratic presidential primaries. Candidates often seek out and woo Rivera, because his 120,000-member union is widely considered the most powerful of all of the state's unions on the national political scene. With its phone banks and printing presses, 1199 often turns out more voters in a statewide primary than any other union.

Two years ago, when Pataki proposed to move all of the state's ***Medicaid*** patients into ***managed care*** during an 18-month period, Rivera urged his friends in the Clinton administration not to grant a waiver. He feared that Pataki's plan would greatly reduce business for hospitals and would cause many hospital employees to lose their jobs.

"That plan would not have worked, because there just wasn't a system of primary ***care*** doctors or clinics in place to serve the ***Medicaid*** population once it moved into ***managed care***," Rivera said. "And a lot of health ***care*** workers would have been dislocated and needed to be retrained."

Recognizing that moving ***Medicaid*** patients into ***managed care*** would save the federal government huge sums, Rivera proposed that the federal government pump a large part of those savings back into New York to ease the transition. Pataki liked the idea because it would mean more federal money. Hospitals backed the idea because it would give them money to build clinics that ***managed-care*** patients would use. Hospital workers liked the idea because part of the money would be used to retrain them to work in walk-in clinics.

After Rivera met with Gore last fall and persuaded him to support a large transition fund, Rivera lifted his opposition to Pataki's request. Then the Pataki administration formed a committee with Rivera's union and Raske's association to rework the governor's ***Medicaid*** waiver plan.

Two years ago, Rivera and Pataki were at loggerheads not only over the governor's plan to move ***Medicaid*** recipients into ***managed care***, but also over his plans to cut health ***care*** spending by more than $1 billion. Rivera's union sponsored a $1 million advertising campaign to attack Pataki's budget cuts, a campaign that caused Pataki to back away from many of those cuts and to seek a detente with 1199.

Praising the role of Rivera and Raske in the ***Medicaid*** waiver deal, state Health Commissioner Barbara DeBuono said: "They were very important to the process. They identified the need for some assistance that could be given to hospitals that would help them survive the transition into ***managed care***."

Principles for Accountable Managed Care

Prepared by:

The Coalition for Accountable Managed Care

American Academy of Pediatrics
American College of Physicians
American Hospital Association
Association of American Medical Colleges
Catholic Health Association of the United States
InterHealth
National Association of Children's Hospitals
National Association of Public Hospitals & Health Systems

PREAMBLE

Over the past decade, managed care has become the dominant force in the organization and delivery of private health care and is growing rapidly in publicly sponsored health care. Although the term encompasses a variety of arrangements and techniques, the hallmark of managed care is the use of financial and other incentives to promote coordinated health care and to reduce costs.

Ideally, managed care has the potential to provide a more seamless continuum of high quality care, expand access to care, and control health care costs. So far, however, managed care performance has been uneven, with evidence indicating both promise and problems. As with fee-for-service health care, incentives for delivering services are not always properly aligned with the needs of patients.

The issue of appropriate standards for managed care — voluntary or mandatory — is the subject of intense debate. Various private entities have developed voluntary standards for managed care. Many states have adopted statutes imposing specific requirements. The federal government has for many years regulated managed care entities participating in publicly sponsored health care programs. As managed care becomes a greater factor in the delivery of health care, government is likely to take an even more active role.

The Coalition for Accountable Managed Care was convened to bring our perspective of patient and community focused health care providers to the public discussion on managed care. The Coalition believes that, to date, the public policy debate with regard to managed care has given too little attention to the core issues of:

- the challenge of increasing numbers of uninsured persons as well as access to health care for all persons, especially those who are poor, suffer from chronic illness, and at special risk
- patient and family needs as the center of the relationship with providers
- the need for accountability to patients and community in the governance of managed care organizations
- the centrality of community needs in providing health care services, and
- the importance of medical education and research in the delivery of health care.

The Coalition developed the following "Principles for Accountable Managed Care" to provide guidelines for public and private policy makers, including federal/state legislative and regulatory bodies, employers and payers, and other standard-setting groups as they design standards for managed care. These Principles are intended to apply to all plans: commercial, Medicare, Medicaid, not-for-profit, and for-profit. Although directed to managed care, the Principles describe obligations shared among all health care providers.

The Coalition believes that no health care provider should be disadvantaged as a result of embracing these Principles and demonstrating its underlying commitment to high value care for patients and communities.

April 1997

Principles for Accountable Managed Care

I. Access to Plans and Services

Managed care plans — whether they serve a broad-based population or have a specialty focus — have an obligation to help ensure timely access to quality health care and appropriate services. Accessibility to plans means reasonable access for persons who are poor, disadvantaged or chronically ill. It also means availability to appropriate specialty care either within the plan or through arrangements with non-plan providers. To promote access to services, health plans should:

1. not discriminate in enrollment;

2. provide, directly or under arrangements, a comprehensive benefits plan and access to an appropriate range of providers and other health resources;

3. have an open enrollment period during which persons may be continually enrolled in a health plan without regard to pre-existing conditions, health history, or health status; and

4. develop explicit criteria for access to specialty care and for the patient's role in decisions regarding specialty services.

II. Quality

Managed care plans can offer improved quality through coordination of care and emphasis on promoting health. However, financial risk arrangements can undermine quality of care. Therefore, managed care plans should encourage clinical excellence by:

1. using professionally recognized standards of quality and appropriateness and meeting recognized certification or accreditation standards;

2. ensuring that the members of the health care workforce providing services within the plan are competent and have appropriate training, credentialing, and experience; and that an appropriate number and mix of health care professionals are available;

3. providing professional autonomy for medical and other licensed health care providers including involving health professionals in decisions concerning coverage of services, quality assurance, and other clinical components of the plan;

4. adopting and implementing quality assurance and improvement mechanisms that are created with the input of physicians;

5. structuring physician/provider financial incentives that support appropriate and high quality care; and

6. initiating, collecting, analyzing, and disseminating information regarding patient care outcomes, patient satisfaction, outcome of grievances, and complaints.

III. Community

Health plans should affirmatively and continuously identify and respond to the needs of their communities. While the appropriate definition of community service will vary among plans, it should extend beyond enrollees and include vulnerable and underserved populations within the plan's geographic area. In addition, plans should be culturally competent. Their programs and services should meet the needs of persons from various backgrounds who have different perceptions and reactions to health issues.

Plans demonstrate accountability to their communities and commitment to community service by:

1. providing benefits to the community in response to community needs, including:

    - efforts to promote health and prevent disease and injury among the enrolled population and in the broad community
    - outreach services provided directly by the plan, by participating providers of the plan, and in collaboration with other public and private service organizations, and
    - the provision of care to persons unable to pay, underserved portions of the community, and high risk patients;

2. advocating publicly for community health promotion and disease prevention policies; and

3. publishing information regarding contributions of the plan to the community.

IV. Health System Improvement

Health care providers and managed care plans benefit from investments in the education of physicians and other health professionals, basic and applied medical research, and innovation in the delivery of health services and public health. To help ensure the continued growth of medical knowledge and its effective application, managed care plans should directly and indirectly support programs and efforts that contribute to the continued improvement of the health care system as a whole.

The contributions expected of a plan include at least:

1. direct funding or participation in funding mechanisms to support medical and other health professional education and research;

2. encouraging medical and health professionals' education and training opportunities at plan-affiliated institutions;

3. participating in studies of health services research, including collecting and analyzing data to develop valid and reliable risk adjustment mechanisms; and

4. participating in community public health initiatives.

V. Consumer Information, Education, and Choice

Managed health care plans have a responsibility to inform and educate consumers. This applies both to the information needed to select an appropriate health plan and to the knowledge required to make effective use of services and options offered by a plan. Managed care organizations should:

1. use marketing and public information materials that are accurate and understandable

2. make available information for selecting a plan, including:

    - premium rates, out of pocket expenses, and other enrollee obligations
    - access to and location of primary and specialty providers
    - financial incentives to participating providers
    - coverage of out-of-plan care, including policies on using specialty physicians and facilities that are not within the plan
    - any services that are excluded and any limitations on the use of services

- appeals and grievance policies that can be used when the enrollees disagree with plan decisions
- quality of care data, i.e., consumer satisfaction, disenrollment rates, and health status measures, and
- percentage of the premium spent on the provision of health care;

3. make available to enrollees information on

- how to obtain referrals
- current list of all providers
- complaint, grievance and appeals mechanisms
- financial incentives to participating providers
- availability and access to specialty services
- ownership of plan and reference to possible conflict of interest situations, and
- how to change providers;

4. ensure that the plan does not limit discussions of clinical issues between patient and provider for financial reasons;

5. give patients opportunities to select and change primary care providers within the plan; and

6. ensure patient confidentiality.

VI. Governance

The governance and advisory structures of managed care plans should represent the interests of the community. Participation by members of the broad community offers a valuable mechanism for understanding and achieving access, community service, and other goals contained in these Principles. Community involvement can include board membership, advisory committees, community forums, and other vehicles for gathering information from community members. The governance of managed care plans should:

1. be clearly identifiable and accountable entities responsible for governing the plan;

2. provide a mechanism for local involvement by community members, employers and other purchasers, physicians and other members of the health care workforce, and institutional providers of care; and

3. publish a mission statement identifying the populations and communities served and the plans' commitment to responding to health care needs in the community as well as to the enrolled population.

VII. Financial Responsibility

The need to conserve resources must be balanced against the obligation to meet the health care needs of patients and the community. By adopting appropriate financial standards and by committing adequate resources to implement these Principles, plans can help ensure that balance is achieved. Specifically, managed care plans should demonstrate financial responsibility by:

1. meeting appropriate federal or state standards related to financial solvency, capitalization, surplus, reserves, deposits, bond requirements, and fiscal soundness;

2. complying with applicable prohibitions against inurement (private benefit), excessive compensation, conflict of interest, self-referral, fraud, and abuse;

3. reinvesting in services and management activities, including information services and quality assurance, designed to improve organizational effectiveness; and

4. budgeting adequate resources to carry out the Principles described above relating to access, quality, community service, health system improvement, consumer choice, and governance.

Brave New Partnerships:

Children With Disabilities
Families &
Managed Care

Acknowledgments

This report is the outcome of a first time collaboration of HealthPartners, a staff model health maintenance organization (formerly known as Group Health, Inc.), through its supporting research organization, the Group Health Foundation, the Center for Children with Chronic Illness and Disability, a national research and training center based at the University of Minnesota, and PACER Center, a parent training and information center. And while this is an unprecedented collaboration, more importantly, it represents a collaboration of a wide variety of people and disciplines who share a common vision: providing family-centered care for children with disabilities and their families. As such, many new relationships have been built that will promote the care of children with chronic illness and disabilities in Minnesota.

From HealthPartners, we acknowledge and thank Barbara Staub, M.D., the director of this project, for her vision and leadership, W. Brooks Donald, M.D., M.P.H., for his skill in bridging with numerous community agencies, Andy Nelson for his constant support and encouragement, Karen Mason for her commitment to families and young people with disabilities, and Kirsten Hase for her work with the complex financial data.

From the Center for Children with Chronic Illness and Disability, we acknowledge the coordination and collaboration of Anne Kelly, M.D., for the planning, program development and research analysis of the project, and Robert Wm. Blum, M.D., Ph.D., for his encouragement, focus and commitment to the larger vision.

From PACER Center, we thank Ceci Shapland for skillful leadership.

Thanks to the Ashby family for allowing us to photograph them.

We also thank Peggy Mann Rinehart who wrote and designed this report and provided all the photographs, along with Linda Pratt, both from the Center for Children with Chronic Illness and Disability, who prepared and revised drafts and provided production assistance. Thanks to Connie Charipar, too, for her print production assistance.

But most of all, we acknowledge and deeply appreciate the time and energy of the families who willingly shared their expertise, information, successes, frustrations and insights about the complexities they face everyday as they seek out the services their children need to live, grow, and thrive.

Sponsors:

The publication, "Brave New Partnerships," has been supported by grant IMCJ27R002-02, "Project Connect," from the Maternal and Child Health Bureau along with grant H133B40019 from the National Institute on Disability & Rehabilitation Research and the Robert Wood Johnson Foundation.

The "Planning Grant to Establish and Integrated Service System in an HMO for Children with Chronic Illness and Disease," has been supported through a grant from The Robert Wood Johnson Foundation made to the Group Health Foundation in collaboration with the Center for Children with Chronic Illness and Disability.

This publication is available in alternative formats upon request. Please contact Peggy Mann Rinehart, Division of General Pediatrics and Adolescent Health, University of Minnesota, Box 721, 420 Delaware St. S.E., Minneapolis, MN 55455.

Table of Contents

Executive Summary

HealthPartners, the Center for Children with Chronic Illness and Disability at the University of Minnesota, and PACER Center completed a nine month planning grant from The Robert Wood Johnson Foundation to understand the range of needs and costs for the pediatric population with chronic illness and disabilities in a managed care environment. They completed:

- *An in-depth interview with 35 parents of children with chronic conditions.*
- *A financial analysis of 410 children within eight categories of chronic conditions.*
- *A survey of HealthPartners physicians to understand their perspective of providing services to young people with disabilities and chronic illnesses.*

In addition, they convened two community working groups—a Parent Advisory Council and a Community Advisory Council.

The political conflict is clear: If HealthPartners provides a more generous or comprehensive benefit package than its competitors, it will cost more and drive out the healthier population to whom the expanded benefit package is unimportant.

The data indicate that most families are satisfied with their child's pediatrician and overall health care. The families, the physicians and the community members participating in this study value relationships with each other. All agree that when physicians, teachers, social workers and the family communicate, the child benefits.

While families appreciate the convenience of having a primary care clinic at the site where most medical care occurs, they report their pediatrician often does not have the time and knowledge to act as coordinator for the child's non-medical needs.

Case management is often mentioned as a desired service by families, physicians, and the Community Advisory Council. While families indicate that their pediatrician is doing a good job coordinating medical care, they also indicate pediatricians are relatively uninvolved with other issues. Case management should represent and advocate for the needs of the child and family in the areas of education, social and community services, in addition to health care.

HealthPartners does not cover all expenses incurred by the family. The costs are currently being underwritten by a combination of HealthPartners dollars, public program dollars, and the public educational system. The areas where the exact sources of funding are unclear include: case management, physical therapy (PT), occupational therapy (OT), speech and language services, home health/personal care attendant (PCA) services, and to a smaller degree, durable medical equipment and medications.

Most families qualify for, or purchase, supplemental coverage for these services. However, the vast majority of those children receive PT, OT, and speech/language services from school. Usually the school pays the cost for these services and they are neither coordinated with, nor reimbursed, by HealthPartners or medical assistance (MA)/TEFRA* programs.

This underscores the larger public policy issue: Who is responsible for paying for the care of children with special health care needs? If HealthPartners provides a more generous or comprehensive benefit package than its competitors, it will cost more and attract more families with chronically ill children than would normally occur, resulting in a competitive disadvantage.

The data indicate that the school system provides most of the occupational therapy, physical therapy, and speech and language services that this population receives. If the parent survey is representative and schools cover between 60–80% of these services, their annual cost for these 410 children within HealthPartners would be between $400,000 and $800,000, two to four times greater than the amount HealthPartners paid for these services over the same period.

HealthPartners, like other health insurance providers, typically bases their benefits on adult, acute, rehabilitative therapies rather than the habilitative needs of children. For adults, PT, OT, and speech/language services are designed to help adults regain function as a result of illness or injury. Since a child often never had the ability, for example, to walk or talk in the first place, they often don't qualify for "rehabilitation." Children with chronic illness or disability

Only two families reported using mental health services, and only two more indicated any problem in accessing needed mental health services.

---

*TEFRA is a Minnesota program that allows families who have children with chronic conditions to receive Medical Assistance so they can continue to receive care at home. Parents make a monthly contribution based on income.

need habilitation and that needs to be reflected in the benefits language or reflected in the services provided by other community entities.

And, like other insurance providers, HealthPartners has different programs and coverage—different products— for different groups who become HealthPartners members. Defining equality of benefits is illusive.

The parent survey reveals that families' median out-of-pocket expenditures are relatively low, though some families experience high monthly costs. The most significant is a monthly fee for TEFRA services which is based on a sliding fee schedule dependent on service utilization and parental income. There are some co-pays for emergency room visits, medications, durable medical equipment and other areas, but families indicate that these payments are generally assumed by TEFRA or are so small that they don't submit them for reimbursement. A greater impact on family finances comes from non-medical sources such as employment changes, special clothing needs, or changes to the home.

Claims processing also causes concern. Families receive many bills from agencies providing services and there is no easy way for families to determine which bills they have responsibility for, which are covered by HealthPartners, and which need a denial letter from the HMO so that the bill can then be submitted to secondary insurance, Medical Assistance, or TEFRA for payment. In these cases, the public agencies systems and private insurer's systems are often incompatible.

Eighty-eight percent of families say they need help with stress management. Of the families reporting this need, two-thirds report that they have not been able to find needed help. Only two families reported using mental health services, and only two more indicated any problem in accessing needed mental health services. Clearly, mental health support services are needed, and the present system of mental health services is not being accessed to meet that need.

Currently, most non-medical case management occurs through the schools and a common response was that the school case load was far too heavy for careful follow through. Families seemed most satisfied when the case manager knew their child well and was a perceived advocate. Too many case managers and frequent changes in them was a perceived problem. ■

Introduction

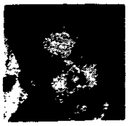
Families whose children have chronic illness and disability must interact with at least three huge and often intimidating bureaucracies: the medical system, the human service system, and the educational system. Rarely do these systems share basic information let alone collaborate on behalf of the child.

By the time each family has filled out the forms for each system, established that their child "fits the category" and indeed qualifies for services, the family's and the child's needs are often lost. While maintaining three isolated systems is costly, no one has collected the exact data to understand which systems provide what services and how much they overlap. No one has assessed the costs of the current model of service provision. No one has described current attempts at service coordination nor identified gaps in service delivery from a parent's perspective.

These families and their children, along with those who depend on Medical Assistance, may be among the first to be enrolled in managed care. If we are to design a managed care system that can effectively and efficiently provide care, we need to know the range of needs and costs for the pediatric population with chronic illness and disabilities.

That's why HealthPartners, the Center for Children with Chronic Illness and Disability, and PACER Center, along with numerous community and advocacy groups, have collaborated to propose a project to establish an integrated service system in an health maintenance organization (HMO) for children with chronic illness and disability. ■

Objectives & Methods



This planning project assessed the current system of health care for children with chronic conditions in a staff-model HMO setting from the perspectives of the provider, the consumer, and community agencies and organizations. The focus of the planning phase was on children with a broad spectrum of chronic conditions and their families. The project was divided into five components: Parent Advisory Council, family interviews, analysis of utilization and cost data, physician interviews, and Community Advisory Council.

The Parent Advisory Council

The Parent Advisory Council (PAC) met four times to describe their family's needs, experiences with HealthPartners, and problems encountered with coordination with other agencies. Discussion was facilitated by Ceci Shapland, R.N., from PACER Center.

Twenty-four families were invited to participate in the Parent Advisory Council. Each has a child:

- *who has had the diagnosis of a chronic condition or disability for at least a year; and*
- *who has been a member of HealthPartners for at least a year.*

Brian Ashby and his Dad

Families are at the center of finding and giving care to their children.

Of the 24 families asked, 13 participated. Refusals were primarily based on a family's inability to make the required time commitment.

The Parent Survey

The project team made an intensive study of 35 families having a child with a chronic condition through the administration of an in-home parent questionnaire.

Forty-four families, each with a child meeting the same criteria as the above, were randomly invited to participate. Those serving on the Parent Advisory Council were excluded. Thirty-five families agreed to participate for an overall response rate of 80%. The parent survey group is predominantly mid-upper income, college educated, European American.

Participants in Parent Survey By Condition & Age

Diagnosis	*Age 1-4 yrs*	*Age 5-11 yrs*	*Age 12-20 yrs*
Cystic Fibrosis	2	2	2
Cerebral Palsy	2	2	2
Trisomy 21 (Down syndrome)	2	2	2
Muscular Dystrophy	1	1	1
Juvenile Onset Diabetes Mellitus	1	1	1
Myelomeningocele	2	2	2
Autism	2	1	1
Blind/Deaf		2	
TOTAL:	12	13	11

Parent Survey

Participants involved in the survey were randomly selected. These families had children ranging in age from one year to 20 years old with a variety of conditions.

The diagnosis set of cystic fibrosis, cerebral palsy, muscular dystrophy, juvenile onset diabetes mellitus, congenital heart disease, autism, trisomy 21 (Down syndrome), myelomeningocele, blindness and deafness was chosen to represent the spectrum of chronic illness in childhood.

The Pediatrician

Families say the primary care physician as coordinator promotes a close working relationship with children and families. Dr. Staub has been Brian's pediatrician since 1986.

Utilization & Cost Data

Utilization and cost data on children with representative diagnoses, as well as the most expensive children in the HealthPartners system, was obtained and analyzed. The data represent all the claims to which the HealthPartners information system had access.

The study identified all children (a total number of 410) who had been HealthPartners members continuously from November 1, 1993, and October 31, 1994, who were between the ages of one year and 21 years-of-age and who were identified with the diagnosis of cystic fibrosis, cerebral palsy, muscular dystrophy, juvenile onset diabetes mellitus, congenital heart disease, autism, trisomy 21 (Down syndrome), myelomeningocele and deaf/blind.*

The services provided to these children and their families were grouped into 16 categories: hospitalizations, HealthPartners professional visits, out-of-plan professional visits, mental health HealthPartners visits, emergency room visits, HealthPartners urgent care visits, lab/diagnostic services, pharmacy, durable medical equipment, physical therapy, occupational therapy, speech, home health, and other.

Denied claims or services received outside of HealthPartners and not billed to HealthPartners (e.g., school,

---

*The diagnoses of deaf/blind had to be dropped because they could not be correctly identified by the current information system.

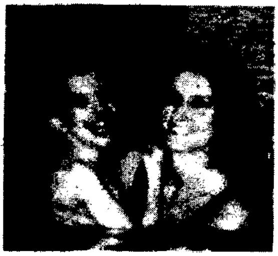
Shriner's Hospital, or claims submitted to another insurance policy) were not represented.

Physician Survey

Physicians from HealthPartners provided their perspectives on the problems and advantages of serving children with chronic conditions in the HMO setting. Twenty-one pediatricians and eight family practitioners from within HealthPartners were randomly selected to complete the written survey. Nineteen pediatricians and two family practice physicians returned the surveys.

The Community Advisory Council

The Community Advisory Council was formed to examine how the system currently functions and to recommend improvements in coordinating services across HealthPartners and other involved agencies, including education and state government agencies. Led by W. Brooks Donald, M.D., M.P.H., 15 representatives from state, advocacy, education, and health organizations were invited and participated in six meetings. In addition, a parent representative, a HealthPartners government programs policy administrator, and three members of the research team attended the meetings. The Community Advisory Council reviewed family needs and interagency barriers within the present system. ■



Recreation

Brian swims every week at Courage Center. Recreation is an important part of maintaining good health for all children, especialy those with chronic illnesses or disabilities.

Family Perceptions & Needs

By and large, HealthPartners families are satisfied with their child's pediatrician and overall health care.

They explain that problems arise when services outside HealthPartners must be coordinated. The referral system, in particular, is often cited as troublesome, not so much that it was difficult to obtain access to outside medical specialists, but that the process was cumbersome.

Results from the Parent Advisory Council

The Parent Advisory Council identified two key areas of strength regarding health services.

- *Pediatrician plays a strong central role as medical care coordinator.*
- *Having a primary care clinic where most medical care occurs is convenient.*

They also identified areas that need improvement.

- *Referral process to out-of-plan specialists is cumbersome.*
- *Claims processing is slow and inefficient.*
- *Case management services are lacking.*
- *There is no perceived source for help with behavioral issues or to deal with family stress.*
- *Parents express concern about future health care coverage.*
- *Information about in-plan resources, policies, and benefits is difficult to obtain.*
- *Care coordination among sub-specialists and HealthPartners pharmacies or laboratories is inconvenient.*

Results from the Family Survey

The Family Survey confirmed and expanded on the issues raised by the Parent Advisory Council: Stress is the most significant issue families face. Clearly, mental health support services are needed for families raising a child with a chronic illness or disability. Eighty-eight percent of families report they need help managing stress. Of these, two-thirds report that they have not been able to find needed help. Only two families report using mental health services; only two report problems in accessing mental health services.

Major Child and Family Concerns

	Parents Reporting Concerns	
	Number	*Percentage*
Stress Management	31	88.6
Future Planning	20	57.1
Special Education	19	54.3
Entitlement Information	19	54.3
Equipment & Supplies	17	48.6
Finding/Working with Physician	17	48.6
Learning	17	48.6
Social/Recreational Opportunities	17	48.6
Dental	16	45.7
Feeding/Nutrition	16	45.7
Behavior or Emotional	13	37.1
Dealing with Agencies	13	37.1
Finance	13	37.1
After School Care	12	34.3
Communicating	11	31.4
Mobility	10	28.6
House Modifications	9	25.7
Respite Care	9	25.7
Coordinating Appointments	8	22.9
Family Counseling	7	20.0
Parenting	6	17.1

Parents Overall Concerns

The 35 families surveyed report a myriad of concerns. Future planning and special education, in addition to stress management, pose major concerns for parents. Most families report many concerns.

Financing

When asked, "Does your child's condition affect your ability to be employed?" just under one-third (28.6%) said "yes." In fact, the greatest impact on family finances comes from non-medical sources such as employment changes. Often, parents who said that their child's condition did not affect employment made comments like the following:

"Because of his condition, I chose not to work."

"No... I stayed out one extra year because of his heart problems..."

"I didn't think anyone in a day care situation would have done the infant stimulation which I did..."

Clearly, decreased employment limits income and therefore limits the amount of money a family has available to meet the family's needs. Additionally, families report decreased employment also increases or is a source of stress.

All families surveyed received their health insurance through their employer but, in addition, nearly one-half (15 families) received additional benefits through state or federal programs such as TEFRA, SSI, Medicaid, Vocational Rehabilitation, WIC, and family subsidies. Pending loss of these programs due to governmental cutbacks is a major source of parental concern.

HealthPartners covers most direct medical expenses. Families report paying from $10 to $42 per month in out-of-pocket expenses. However, the vast array of habilitative services are covered by supplemental coverage or are provided in the school setting.

Families, physicians, and the Community

Trips to Courage Center

While physical therapy is often provided through the schools, Brian receives additional therapy at Courage Center. HealthPartners pays the bill.

Services and Funding Sources

Services	*Number Receiving Services*	*Health Partners*	*TEFRA*	*School*	*Other*
Occupational Therapy	19	3	3	16	1
Physical Therapy	15	5	4	10	1
Speech & Language	13	-	4	10	1
Skilled Nursing	3	1	2	1	1
Personal Care Attendant	12	-	7	2	4
Respiratory Therapy	6	3	2	1	-
Mental Health	2	2	-	-	-
Medication	28	24	11		21
Durable Medical Equipment	12	9	6	-	-

Advisory Council agree that case management services are desirable. However, some parents said they received too much case management. Often, each agency has its own case managers: school, county, health care provider. These case managers can only advocate for a child in one area or concentrate their case management to serve as a gatekeeper for their agency's resources.

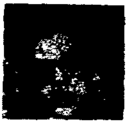
Case management should represent and advocate for the needs of the child and family in the areas of education, social and community services, in addition to health care. ■

Services

A staff model HMO like HealthPartners does not cover all services for children with chronic illness or disability. Physical therapy, occupational therapy, speech and language services are currently being provided by the school with a smaller portion covered by TEFRA or Medical Assistance. Some children receive services at more than one location.

HealthPartners, like other health insurance providers, typically base their benefits on adult, acute, rehabilitative therapies rather than the habilitative needs of children. For adults, PT, OT, and speech/language services are designed to help adults regain function as a result of illness or injury. Since a child often never had the ability, for example, to walk or talk in the first place, they often don't qualify for "rehabilitation." Children with chronic illness or disability need habilitation and that needs to be reflected in the benefits language.

Cost & Utilization Analysis



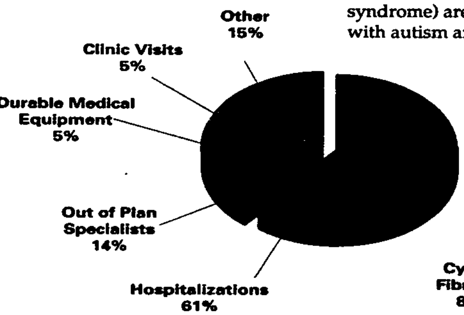
The annual cost of HealthPartners care to the 410 children meeting the study criteria was just over $6.2 million. This is an average of $15,122 per child. Almost two-thirds, or $4.15 million, was spent on hospitalization. Further analysis shows that the 25 "most expensive" children accrued hospital costs ranging from $15,633 to $770,060. Clearly, hospitalization is the single most expensive service provided to children and their families.

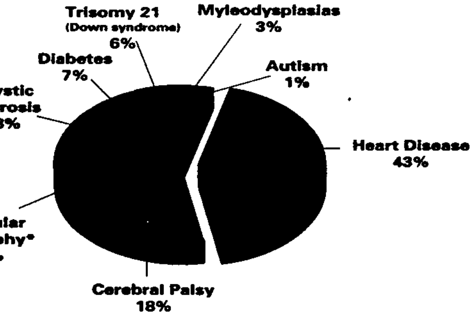
Some disabilities and chronic illnesses like cystic fibrosis, heart disease and, in this study, muscular dystrophy* have a high rate of hospitalization. They are the most expensive conditions for HealthPartners to manage.

Other conditions such as autism and trisomy 21 (Down syndrome) are less expensive for HealthPartners. Children with autism and trisomy 21 require specialized school services and more in-home support. Likewise, there is a range of expenditures among conditions. Children and youth with cystic fibrosis, for example, have no expenses for physical, occupational, and speech therapies. ■

Cost by Expense Category

Clearly, hospitalization is a major reason children and youth with chronic illness and disability are costly. Occupational therapy, physical therapy, medication, outpatient diagnostic or lab work, emergency room visits, speech and language services, those included in the "other" category, represent a lesser expense.





Cost By Disease Category

Conditions associated with a high rate of hospitalizations were associated with a disproportionately high expense.

---

*One patient with muscular dystrophy was responsible for $889,861 of the $961,440 total cost for that condition. If that patient were excluded, muscular dystrophy would fall to the fifth most expensive of the eight diagnoses studied.

Physician Survey

Most physicians in the study say they follow fewer than 20 children with complex medical conditions or physical disabilities. However, they also state that six to 20 percent of their time is devoted to caring for these young people.

Most say they enjoy caring for the child's medical needs. They believe HealthPartners provides a broad benefit package to these children and offers care coordination which is superior to other health care systems. As primary care providers, they feel informed and able to coordinate and guide appropriate care.

Still, the majority believe coordination with other providers, agencies, and schools is time consuming and difficult. The majority say they do not know for sure how equipment, supplies or special services will be paid for, if not by HealthPartners. They also say it is often difficult to locate needed services. Many physicians feel they do not have enough time to spend with complex patients to review subspecialists' reports, to evaluate medications, and to coordinate care. ■

Physical Therapy

Therapy helps Brian to function at the best level he can. Unlike those children and adults who sustain a physical disability because of illness or accident, Brian was born with cerebral palsy. He has no function to regain.

Community Advisory Council

The Community Advisory Council identified problems within the community in order to describe barriers families face. Interestingly, the recommendations from the Community Advisory Council for changes within the HealthPartners system echoed those made by families and physicians.

Case management is important. However, the Community Advisory Council agrees that current case management focuses on management of costs and utilization for the specific agency. Rarely does one work as an advocate for the child and the family. There is poor communication between systems.

The notion of "health care reform" creates anxiety. Agencies protect their "turf," fear budget cuts, and therefore fear collaboration. Families, in turn, are anxious about changing restrictions and eligibility requirements. They fear the loss of programs like TEFRA that have funded critical, often expensive, services. ■

In-Plan Specialists

Brian visits the pediatric ophthalmologist regularly. These visits are part of the HealthPartners benefit package.

Discussion and Recommendations

The families, the physicians, and the community members participating in this study value relationships with each other that are based on mutual respect and trust. All agree that when physicians, teachers, and social workers communicate, the child benefits.

All agree that:

- *families and providers need to make placement and treatment decisions that support and empower families rather than safeguard agency ideology or funding.*
- *caring for a child with a chronic condition within the context of the family and the community is more successful than simply treating a disease.*

Families report that their greatest stress comes from arranging for multiple services through multiple agencies for their children with chronic conditions. The present study underscores this finding: there is little collaboration among the medical, social service and education communities.

Part of the lack of coordination is due to fragmented funding. While HealthPartners covers most direct medical expenses, there is still debate about who should fund certain health-related services such as durable medical equipment, occupational, physical and speech therapies, home care services—ranging from respite care and personal care attendant services to respiratory care and nursing care. Is this the responsibility of the federal government? The state government? The school system? And we still don't know if the various therapies and family services reduce the overall costs of these expensive children.

Finally, this present study points out that managing the stress that comes with caring for a child with a chronic or disabling condition is the number one concern for most families. Of the eighty-eight percent of families who say they need help managing stress, two-thirds have been unable to find the help they need.

What Can HealthPartners Do?

The Community Advisory Council, the Parent Advisory Council, along with the families interviewed and physicians surveyed, agreed that staff model HMOs like HealthPartners need to develop strategies that promote the overall health and well-being of children with chronic illness and disability and their families. They make the following recommendations to HealthPartners:

1. Expand case management and care coordination so that:

- A care coordinator works with a physician to improve the care the family is receiving;
- A care coordinator investigates resources that are unfamiliar to the physician and the family, and identifies those resources that are most beneficial; and
- A care coordinator links families with community services.

2. Advocate for an industry-wide acceptance of benefits based on the needs of children so that:

- The development of children with disabilities is not stymied by a benefits package based on adult needs;
- Benefits are flexible and allow for individual family and child needs; and
- Benefits are presented clearly and applied consistently across disease groups.

3. Increase the coordination of care within HealthPartners so that:

- Referrals are streamlined for the special needs population;
- Referrals are designated for a specific period of time;

- Claims and billing information are simplified; and
- At least one member of the claims department is trained to answer questions specifically regarding children and youth with disabilities.

---

4. Provide a special orientation of HealthPartners for families with children and youth with disabilities so that:

- Families understand resources available through the system and how to access them, including continuing care, mental health services, social work services, and case management;
- Families learn how to appeal the system; and
- Families feel they are heard.

---

5. Promote the use of mental health services so that:

- Outside consultation is available to families working through the issue of having a child with a chronic condition; and
- Pediatric health psychologists are available and familiar with the needs and stresses of families.

---

6. Expand the hours of service to help meet working family's needs and minimize loss of school time for the children.

What Can Communities Do?

It really does take an entire community to nurture, care for, and raise our children—especially those with chronic illness or disability. Many of the recommended changes in health care systems and clinical care can be addressed without government or agency edict. Often, all that is required is for professionals, aware of the issue, to make the changes.

The following recommendations address issues that are "external" to specific health care delivery systems and clinics yet are considered essential for a community if children with chronic illness or disabilities and their families are to thrive.

1. Separate agency-focused case management from independent family-centered care coordination.

☐ Families should have access to independent care coordination and family advocacy, that is family-centered, community-based and culturally sensitive.

2. Develop easy access to information, support, referral and advocacy for both families and providers.

☐ Develop a telephone information service.

☐ Develop a computer-based information system.

3. Improve communication between agencies and health systems.

☐ Educate practitioners to plan for and respond to families' anxiety as systems change.

☐ Allow for thoughtful and seamless transition when shifting between public and private funding systems.

4. Understand that health care is a market driven enterprise.

☐ Establish incentives for individual health care systems that reward creative methods of serving children with chronic illness or disabilities.

☐ Advocate for a safety net of expanded benefits and limitation of cost sharing co-payments for families.

---

5. Avoid cost shifting.

☐ Monitor short- and long-term outcomes and costs to all aspects of the system, including the family.

☐ Encourage creative financial models or pilots that involve more community and family-controlled decision-making.

☐ Create a health care financing system that encourages competition for serving children with chronic illness or disabilities.

Conclusion

There is agreement that further research is needed in order to develop and test criteria needed to assess the quality of children's health in general and those elements that will result in quality care for children with chronic conditions within managed care environments. Proponents argue that managed care is the optimal setting in which to develop integrated, coordinated, community-based and family-centered services.

Currently, at HealthPartners the medical needs of children and youth with chronic illness and disability are being met with good primary care at the child's home clinic and specialty care covered by the plan.

Some bemoan the pitfalls of applying managed care models to children with chronic conditions; however, this is the first study that takes a hard look at how families with children who have chronic illness and disability and their families are faring. The news is mixed. Families are doing well; HealthPartners clearly provides more coordinated services than a fee for service basis. Still, families are relying on a hodgepodge of financing that may be dramatically reduced in the near future. They are surviving, but families really need access to more information, more interagency coordination, and more preventive mental health services if they are to thrive. ■

Collaborators

Advisory Board

Barbara Staub, MD
HealthPartners Pediatrician
Project Director

Robert Wm. Blum, MD, PhD
University of Minnesota

Ceci Shapland, RN
PACER Center
Parent Advisory Council Chair

W. Brooks Donald, MD, MPH
HealthPartners Pediatrician
Community Advisory Council Chair

Anne Kelly, MD, MPH
Assistant Professor
University of Minnesota

Andrew Nelson, MPH
Group Health Foundation
Executive Director

Cathy Wisner, PhD
Group Health Foundation
Research Investigator

Karen Mason, RN
HealthPartners Pediatric Case Manager

Community Advisory Council

Phyllis Brenneman, Department of Human Services

Wendy Berghorst, West Suburban Early Intervention

Anne Damon, Children's Initiative

Barb Donaghy, Children's Health Care-St. Paul

W. Brooks Donald, M.D., M.P.H.

Carolyn Elliott, Special Education

Mark Faitek, Social Security Administration

M. Catherine Griffith, Health East

Mary Kay Haas, Department of Education

Bill Henry, Pathfinder Resources, Inc.

Diane Hovey, Parent

Jan Jernell, Minnesota Department of Health

Georgianna Lee, Pathfinder Resources, Inc.

Kathleen Murphy, Department of Human Services

Ann Rogers, HealthPartners/Government Programs

Nan Satterlee, Robbinsdale Area Schools

Ceci Shapland, RN, PACER Center

Nancy Vanderburg, Minnesota Department of Health

Staff:

HealthPartners: Barbara Staub, MD; W. Brooks Donald, MD, MPH; Andrew Nelson, MPH; Kirsten Hase; Brita Hedblom

PACER Center: Ceci Shapland, RN

Center for Children with Chronic Illness and Disability: Robert Wm. Blum, MD, PhD; Anne Kelly, MD, MPH; Peggy Mann Rinehart

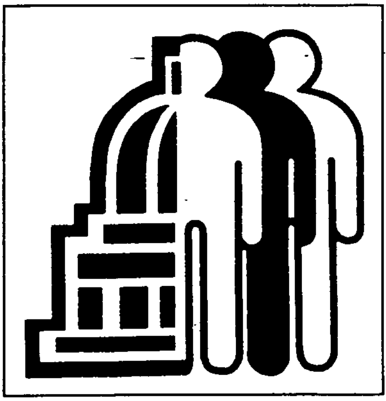
KEEPING FAITH

SYSTEM CHANGE, MANAGED CARE, AND LONG-TERM SUPPORTS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

A Working Document

December 1996

National Association of State
Directors of Developmental
Disabilities Services, Inc.



About this document

Over the past two years, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) has devoted a considerable amount of time and resources to assessing the pros and cons of using managed care techniques to reconfigure the delivery of services and supports to people with developmental disabilities. Among the results of this work to date are:

- the preparation and distribution of the nation's first comprehensive position statement on managed care and long-term supports for individuals with developmental disabilities;
- the publication of a groundbreaking guidebook on managed care and developmental disabilities services,* which has been widely acclaimed and frequently cited as the seminal work on the subject;
- the co-sponsorship of six national and statewide training seminars on managed long-term supports,* as well as participating in literally scores of similar workshops and meetings sponsored by other organizations; and
- the provision of technical assistance to more than a dozen states that are in various stages of exploring the prospects of restructuring their MR/DD service systems along manged care lines.

Based on these experiences and the realities of the current public policymaking environment, we are convinced that:

(a) over the next few years many states will be forced to restructure the financing and delivery of long-term supports to persons with developmental disabilities in order to avoid a steady deterioration in the quality and accessibility of services; and

(b) the intelligent, value-based adaptation of managed care techniques can play an important role in enabling public developmental disabilities systems to respond effectively to this challenge.

---

* This work was undertaken in collaboration with the Human Services Research Institute, Inc. of Cambridge, Massachusetts.

We recognize that managed care is fraught with uncertainty and peril. However, we also are convinced that, unless public developmental disabilties service systems become more cost-effective and accountable for valued outcomes, they will be less and less able to fulfill their mission and be increasingly subject to privatization. In the absense of a forthright response to these issues, we are profoundly concerned that existing service systems will be absorbed into managed care arrangements that serve interests other than those of the individuals and families who are the intended beneficiaries. If managed care comes to public MR/DD service systems, all key stakeholders should be involved in designing the state's basic approach in order to assure that the best interests of people with disabilities and their families remain paramount.

This white paper summarizes NASDDDS' views regarding the basic challenges which public MR/DD service systems face today; it explains why we believe that such systems will have to be realigned and outlines the principles and policies that should guide this realignment process. The paper is labelled a working document because it should not be viewed as the final word on the subject. Instead, our aim is to stimulate discussion and debate within the community of individuals who are committed to the values we share. These values are reflected in the Association's mission statement and guiding principles, which specify in part that NASDDDS will "...assist member states to build a person-centered system of services..." in which "...people with developmental disabilities have a right to:

(a) be treated with dignity and respect;

(b) be independent and make individual choices;

(c) participate in family and community life;

(d) have opportunities to maximize their full potential; and

(e) receive outcome-based services and supports."

CURRENT POLICYMAKING ENVIRONMENT

Nationwide, hundreds of thousands of indiviuduals with developmental disabilities and their families rely on long-term services and supports provided through publicly-funded developmental disabilities service systems. The central mission of these systems is to enable individuals with developmental disabilities to live and work in their communities, achieve self sufficiency, and excercise their full citizenship rights.

Over the past two decades, states have made major strides in improving the quality and cost-effectiveness of publicly-funded developmental disabilities services. The number of individuals residing in costly, segregated public institutions has been cut in half and scores of such facilities have been closed. States have aggressively expanded their home- and community-based waiver programs while de-emphasizing the development of expensive intermediate care facilities for persons with mental retardation and related conditions (ICFs/MR). States also have initiated and rapidly expanded family support and supported living and employment programs that more effectively meet the needs of their customers and make better use of scarce public dollars. More attention has been focused on improving the quality and accessibility of publicly-funded services as well.

A great deal has been accomplished, but much more remains to be done. Trapped between rising consumer expectations and tighter budget constraints, public MR/DD service systems today face enormous challenges, including:

- **Limitations on federal Medicaid payments to the states.** Currently, federal-state Medicaid dollars underwrite 70 percent of the operating costs of public developmental disabilities systems. But with both President Clinton and Republican and Democratic Congressional leaders supporting a balanced federal budget, legislative steps to contain the growth in federal Medicaid outlays are inevitable. Reduced access to federal Medicaid dollars will have serious consequences for developmental disabilities services as well as the public system's capacity to respond to the legitimate needs of people with developmental disabilities and their families.

- **State Medicaid cost containment initiatives.** States are intensifying their efforts to contain Medicaid spending, particularly through the application of managed care approaches across a wider spectrum of Medicaid recipients and services. Accounting for 35 percent of all Medicaid spending, long-term care services -- including Medicaid-funded ICF/MR and home and community-based services for people with developmental disabilities -- are not likely to be exempt from these cost containment initiatives.

- **Shifting federal and state budget priorities.** Federal domestic assistance is being cut in order to reduce the federal deficit. Furthermore, human services programs are being assigned lower priority in some states due to other pressing budgetary priorities.

- **Waiting lists.** Despite the steady growth in funding for developmental disabilities services over the past decade, most states today have long waiting lists for services. In some states, these waiting lists have climbed so high that individuals have little prospect of receiving services except in dire emergencies.

- **Growing demand.** Service demand will continue to grow for the foreseeable future due to a host of complex demographic factors, including the increased longevity of individuals with severe disabilities and the higher expectations of families that have had access to early intervention and special education services during their children's formative years.

Public developmental disabilities systems face a turbulent, challenging and unsettled future. At stake is their ability to respond to the critical needs of individuals and families in a timely, reliable, and effective manner.

The widening gap between available resources and consumer demand is confronting state and local officials with thorny policy choices. Should the gap be closed by narrowing eligibility for services? Should the range of services and supports be cut back? Should access to certain services be narrowed? Should systems operate on a triage basis?

These choices have enormous implications for the future role and mission of public developmental disabilities systems.

There is a distinct possibility that public developmental disabilities systems will be swept up in broader statewide managed care initiatives. If so, the result could be narrower access to specialized developmental disabilities services and the substitution of generic assistance that is not well suited to the purpose. There are legitimate fears that under managed care, essential values -- individual and family choice, community integration, and person-centered service delivery -- would be subordinated to economic interests.

The application of managed care concepts and approaches must be based on solid public policy principles, goals, and objectives. Managed care can work in the best interests of individuals and families only when it is employed as an instrument to secure improved efficiency, measured against performance and outcome standards that embrace essential policy goals and values.

THE SYSTEMS CHANGE AGENDA

If public systems are to keep faith with their fundamental mission of furnishing effective supports to people with developmental disabilities and their families, **all system stakeholders must confront today's harsh realities and agree on systematic changes** that will place such systems in a better position to carry out their mission. The consequences of failing to act are very high.

A central element in this system change agenda must be productivity improvements -- i.e., optimizing services and outcomes within the constraints of a global budget. The resolute pursuit of this objective is absolutely necessary if public systems are to withstand pressures to define away the problem by narrowing eligibility or constraining access to essential services. Faced with the prospect of capped funding and rising demand, **public systems must adopt "what's needed, no more, no less" as a practical operating philosophy.**

Current public systems are burdened with both state- and federally-imposed rules, regulations, and funding methods that create enormous barriers to the cost-efficient delivery of services and supports to individuals with disabilities and their families. Funding streams are categorical and fragmented. Slot management approaches often result in a "one size fits all" system which furnishes people with what is available not what is most cost-effective or what they really want.

Fee-for-service payment systems penalize service providers for using dollars more efficiently and create other barriers to flexibility and agility in delivering person-centered supports. The regulation of service systems remains grounded in process and paper. **New approaches to rewarding exemplary performance and achieving valued outcomes must be developed.**

As a result of federal policies and other factors, many public developmental disabilities systems are over-invested in costly service models. The financial burden of maintaining such models has foreshortened the capacity of service systems to respond to the needs of youth transitioning from school to adulthood or to step in promptly to meet the needs of individuals when their families no longer are able to provide supports. **States need to accelerate the shift away from costly service models by emphasizing publicly-funded supports that are blended with other natural and community supports.**

System change is threatening. It is marked by turbulence and uncertainty. However, it is abundantly clear that, **unless productivity is improved, public developmental disabilities systems will be less and less able to carry out their mission.** Waiting lists will become longer and longer. It will become increasingly difficult to provide high quality services and supports. **Maintaining the status quo will have particulary disastrous consequences for people who need supports but are locked out of the service system.**

System change must be anchored in and constantly referenced to the essential mission of public systems: supporting people with disabilities to live everyday lives in their communities. System change must be continuously informed by person- and family-centered values.

A MANAGED CARE APPROACH TO RESTRUCTURING SERVICE SYSTEMS

The intelligent, informed, value-based adaptation of managed care approaches can serve as a platform for reconfiguring and, thereby, improving the productivity of public developmental disabiities systems and strengthening the emphasis on valued outcomes. Managed care approaches -- intermediaries responsible and accountable for systewide performance, capitation and risk assumption, managed utilization of costly services, cost savings incentives, and performance indicators -- provide promising tools for system improvement.

Managed care techniques can help public developmental disabilities systems to replace fragmented, categorical funding with single-stream approaches that deploy dollars more flexibly to meet the unique needs of each individual. System incentives can be created to foster improved productivity. Managed care offers new opportunities to reconfigure systems along customer-driven and directed lines. Process regulations can be replaced by objective measures of the service system's performance in achieving desired public policy outcomes.

Still, there is scant experience in applying managed care strategies to the delivery of long-term services and supports. Important differences exist between the delivery of long-term supports and health care services, where there is more experience with managed care approaches. Health care touches one aspect of an individuals life; long-term supports, in contrast, affect many different facets of an individual's life. Moreover, experiences with managed health and mental health care raise important cautions concerning the interplay between economic incentives and maintaining the integrity of service delivery.

In public developmental disabilities systems, **the introduction of managed care must be approached cautiously** and with full recognition that new and distinctive managerial strategies will be required to successfully adapt managed care technology to the needs of people with life-long disabilities and their families. **It is enormously important that system stakeholders play a central role during all stages of defining how such techniques are to be applied** if the end result is to be a service system that advances shared beliefs and leads to valued outcomes.

INSTITUTING A MANAGED CARE SYSTEM

Any attempt to accomplish systemic change through a managed care approach must be framed by public policies that clearly articulate the central goals of the public system while ensuring that the interests of people with developmental disabilities and the public at large are protected. A suggested policy framework for the introduction of managed care to MR/DD service systems is outlined below.

Managed Care Framework

- *The central mission of the public system should be to enable individuals with developmental disabilities to live everyday lives, achieve self-sufficiency, exercise self-determination, and become integral, valued members of their communities;*
- *Individuals, families, and service providers should maximize the use of natural supports and other community assets in meeting the needs of each person;*
- *Individuals and families should have access to necessary and effective services and supports consistent with the limitations imposed by available resources;*
- *The responsibilities of the public system in responding to individuals in crisis should be clearly delineated;*
- *Family supports should be emphasized, both as a means of making more effective use of scarce resources and as a firm foundation for building circles of community support for individuals with disabilities;*
- *Individuals and families should be given the option of directing the delivery of services and supports within reasonable policy parameters;*
- *The service system should be managed on the basis of performance and outcomes;*

Managed Care Framework (Cont'd)

- *Consumer rights should be clearly articulated and consistently applied;*
- *Protections of individual health and safety should be vigorously enforced without compromising individual control and self-determination;*
- *Consumers and families -- as well as other stakeholders -- must be granted ample opportunity to participate in system redesign, procurement decisions, oversight, and evaluation;*
- *Cost savings which are achieved through system restructuring should be earmarked for waiting list reduction and/or quality improvement initiatives; and —*
- *The system should be fully accountable to consumers, public officials, and taxpayers, including continuous legislative oversight of the design, implementation, operation, and outcomes of the new system.*

A well-articulated policy framework is absolutely vital to ensuring that managed care concepts are instituted in a manner that serves the best interest of individuals with disabilities, their families, and the general public.

MANAGED CARE DESIGN PRINCIPLES

The introduction of managed care approaches to the delivery of publicly-funded services and supports for people with developmental disabilities must be framed by the public policy principles outlined above and ~~be~~ the end-product of a design process that is grounded in the following guidelines and principles:

- All state and federal funding for long-term services and supports to people with developmental disabilities should be consolidated in order to promote integrated service delivery and global system management;
- Such funding should be carved out (rather than folded into a broader managed care system) and administered under a separate plan that is crafted specifically to meet the long-term support needs of individuals with developmental disabilities and their families. This plan should include formal mechanisms for coordinating the delivery of developmental disabilities services with those managed by other public systems that affect the well-being of such individuals, including health care and mental health services;
- The developmental disabilities service authority (DDSA) in each state, in partnership and collaboration with individuals, families, and other stakeholders, should play a central role in designing, implementing, and operating the system. DDSAs, in tandem with other responsible

state agencies, must be held accountable for plan perfomance. The DDSA also must be equipped with the authority and the resources to manage the system, including the enforcement of contractual requirements, evaluation of system performance and outcomes, protection of consumer rights, and the assurance/improvement of service quality;

- The managed care plan must clearly define: (a) eligibility; (b) the services and supports to be furnished to eligible individuals; (c) the obligations of managed care entities in ensuring the timely, effective delivery of benefits defined in the plan; (d) standards for the procurement of managed care entities; (e) consumer rights (including prompt resolution of consumer grievances); (f) service provider credentialing standards; (g) the methods to be used in collecting and employing performance and outcome data; and (h) risk sharing arrangements;

- The plan should seek to provide all eligible individuals with access to needed and desired supports. To the extent that resources are inadequate to support the delivery of necessary services to all enrollees, the plan also should specify the strategies for achieving universal access to supports within legitimate time frames, including methods of redeploying the savings resulting from productivity improvements;

- Service decisions should be based on person- and family-centered assessments and planning processes anchored in the fundamental public policy aims that frame the system;

- The plan must provide for consumer-directed options that enable individuals and families to self-managed supports. These options may include vouchers, individual budgets, cash and counseling approaches, and other recognized and accepted models of support that will enable individuals and families to excercise self-determination, encourage the development of consumer collaboratives that make it possible for individuals and families to work together as a "purchasing block", and expand the network of supports beyond traditional service providers. The use of these options must be subject to appropriate safeguards. Accountability for the use of public funds must be retained;

- The plan should be based on decentralized decision-making and community-based management in order to foster effective interaction with natural and other community supports;

- Individuals and families must have *bona fide* choices among service agencies, including non-traditional vendors. Managed care organization procurement policies should foster comprehensive provider networks/panels;

- Capitation methods must be risk-adjusted to ensure that funding is adequate and, consequently eligible individuals, regardless of the severity of their disability, are able to access needed services and supports;

- Risk bearing arrangements should be phased-in gradually. Provisions should be made for the use of stop-loss, reinsurance, and other risk sharing arrangements in order to reduce potential conflicts of interests in meeting the needs of individuals who require intensive services and supports;

- Plans must contain adequate provisions for rapid-response crisis services, including clearly fixing responsibility within the system for the provision of such services;
- Individuals and families must have access to grievance and appeal mechanisms designed to fairly and rapidly address disputes arising from decisions made by the managed care entity and the individual/family;
- The plan must contain appropriate and adequate safeguards to ensure access to a broad range of services and supports, includng "grandfathering" participation by existing providers during initial implementation and having appeal mechanisms for use when providers are adversely affected by the contracting decisions of managed care entities;
- Managed care initiatives should be implemented on a multi-year basis, employing, whenever feasible, pilot projects and interim milestones to assess the soundness of the approaches being undertaken; and
- Procedures should be included for updating the managed care plan as well as the contracts implementing the plan in order to accommodate lessons learned and make necessary adjustments in provider payments.

Careful system design, based on the preceding guidelines and principles, is absolutely essential to ensuring that a coherent, well-articulated and accountable managed care system operates in the best interests of individuals, families and the general public.

MANAGED CARE ORGANIZATIONS

The selection of entities to serve as managed care organizations is enormously important. These entities play a pivotal role in any managed system. Public policies governing the procurement of such entities must ensure that managed care organizations meet minimum standards and demonstrate essential capabilities. People with disabilities and their families should play a substantive role in the selection process. These standards include:

Policies Governing MCO Procurement

- *A mission-based, person- and family-centered organizational philosophy;*
- *Demonstrated experience in managing the delivery of services and supports for people with developmental disabilities;*
- *The delineation of, and a central role for, people with developmental disabilities and their families in organizational governance, quality improvement, and evaluation;*

Policies Governing MCO Procurement (Cont'd)

- *A commitment to promoting innovative support strategies, including consumer-directed alternatives;*
- *A solid track record in working constructively with service provider agencies to achieve improved performance and responsiveness;*
- *Clear organizational capabilities to fulfill the requirements spelled out in the procurement specifications that are based on the managed care plan;*
- *Demonstrated capabilities in establishing effective and productive linkages with other community resources and organizations;*
- *Financial solvency;*
- *A well-articulated quality assurance and quality improvement plan;*
- *Willingness to contract on a performance basis, including the use of incentives and penalties based on negotiated benchmarks that address access to services, timely response to consumer needs, consumer satisfaction, and desired outcomes; and*
- *An effective management information system, plus appropriate equipment and technological capabilities.*

In selecting managed care entities state policies should give preference to non-profit organizations and/or existing, statutorily recognized local administering agencies.

In addition, states should encourage the development of multiple, locally-based managed care organizations in order to foster effective ties to local communities.

CONCLUSION

Public developmental disabilities service systems must confront the enormous challenges posed by modifications in federal and state policies which are likely to impose strict limits on the dollars available to meet current and future service demand. These systems must embrace productivity improvement as a central goal while keeping faith with their core mission and values.

Managed care approaches can be valuable tools in unifying existing service systems and allowing them to deliver "what's needed, no more, no less" effectively and efficiently. Service systems must be designed to advance the essential public policy aim of enabling people with developmental disabilities to live full, productive, self-determined, everyday lives in their communities. Individuals with disabilities, their families and other stakeholders must participate in the redesign process and have meaningful roles in the ongoing management of the system. The central aim should be to create a system grounded in person-centered support principles, including consumer-managed, consumer-directed service alternatives, that offer real opportunities to link natural and other community resources with public supports to best meet the needs of the target population.

These outcomes will be achieved only if the redesign process itself is informed by critical principles that ensure the coherent adaptation of managed care approaches to long-term supports for people with developmental disabilities. It is essential that the organizations chosen to carry out this redesign be carefully selected so that all stakeholders can be confident that the resulting service system will operate in the best interests of individuals and families.

Research Agenda Brief

January 1996

Why Not the Best for the Chronically Ill?

Prepared by

Stanley B. Jones
Director
Health Insurance Reform Project

Health Insurance Reform Project, George Washington University
Prepared with support from the Commonwealth Fund

The George Washington University
WASHINGTON DC

Summary: Premium adjustors to neutralize risk selection among health plans are the weakest component in the technology for assuring competitive markets. It will be many years before we have adjustors adequate to free health plans to invest in and market improved managed care to predictably high-cost chronically ill persons. For want of a fair premium, health plans are driven by risk selection to underinvest in and otherwise "demarket" care to these very employees and beneficiaries whose costs and care most need to be managed. To achieve best value for the chronically ill, large employer coalitions, Medicare, and Medicaid should consider radical new approaches, such as establishing separate prices for care to people with specific chronic conditions and purchasing such care both from health plans and directly from provider systems.

Chronic conditions involve health care needs that seem particularly suited to the kind of improved coordination and capitated payment associated with managed care. Such conditions often require the patient to deal with numerous and varied providers of services over a protracted period of time. In addition, they frequently involve a progression (often downward) over time that requires adjustments in services—to both accommodate to and retard further loss. And they affect patients differently —often requiring very tailored services. In many cases, patients must comply with complex instructions to avoid acute episodes or more rapid deterioration. Health care providers need clinical time to work with such patients —and flexibility to organize care to meet individual needs—beyond that provided under the usual acute medical care fee schedule and coverage categories.

Moreover, the chronically ill incur high costs for employers and public programs. Health care costs for persons with moderate chronic disabilities, for example, may be as much as two to three times higher than those for persons without disabilities.[1] In addition, the morbidity associated with chronic conditions costs employers a great deal in absenteeism and lost productivity.

Given the opportunity managed care seems to offer for the chronically ill, employers, Medicare, and Medicaid by all rights might hope to see health plans competing to develop and market higher-quality and more cost-effective plans for chronically ill employees. Purchasers might hope to see plans advertising aggressively to enroll chronically ill employees and beneficiaries, and they might well want to help channel these employees and beneficiaries to the plans that offer the best value. This hopeful scenario is not justified by the incentives in today's health plan market.

ADVERSE RISK SELECTION AND ITS CONSEQUENCES

In the market of competing health plans, the threat of adverse risk selection encourages health plans to be at best ambivalent about investing in care for the chronically ill. On the one hand, such investments offer great potential for reductions in costs and improvements in value. But on the other hand, if a plan becomes known among employees or beneficiaries as better than its competitors at caring for people with a particular chronic condition, it is likely to attract more such subscribers during open seasons, and its costs and premiums are likely to rise in comparison to its competitors'. This is because, in serving people with chronic conditions, it is hard to be so efficient that the cost of care to a chronically ill enrollee is at or below the average for a plan's enrollees. Ultimately, a plan cannot quote a competitive premium if it enrolls many more than its proportionate share of sicker employees or less than its share of healthier employees.

The importance of risk selection in determining premiums of competing health plans was first documented publicly in the Federal Employees Health Benefits Plan (FEHBP). In 1989, the actuarial values of nine FEHBP plans studied varied by no more than 35%, but the premium of the highest-cost plan was 246% greater than the lowest-cost plan, due primarily to adverse selection. The high-option and standard-option Blue Cross and Blue Shield plans were virtually identical in benefit value, but the high-option premium was nearly twice the standard option's due to risk selection.[2] Wide variation in benefit value compared to premium among very similar health plans is common where employees or beneficiaries are given the choice of multiple plans. Risk selection therefore can produce much larger variations in premiums than the 15% to 20% estimated savings achievable by the most tightly integrated health maintenance organizations.

The implication of this phenomenon for health plans' competitive strategies is that *health plans can not rely on efficiency alone; they must compete based on risk selection.* If plans were to advertise to enroll the chronically ill, or if Medicare, Medicaid, or employers were to channel beneficiaries or employees who are chronically ill into health plans that offer the best value (price and quality), or if large numbers of the chronically ill were to learn about these plans and seek them out, these plans' competitiveness would be damaged. Because of risk selection, (*a*) health plans are not motivated to compete to market better value to the group purchasers' most costly and needy employees or beneficiaries, and (*b*) the group purchasers would harm the best plans if they encouraged their most costly and needy employees to enroll in them.

"DEMARKETING" TO THE CHRONICALLY ILL

How many health plan advertisements have you seen aimed at recruiting high-cost chronically ill people? With regard to the chronically ill, health plans have a strong incentive to demarket—or at least to "stay in the pack" of competing plans, that is, neither to stand out as a better value nor to appear scandalously behind.

Such a posture argues for investing less, at the margin, in improvements or plan features that increase value to the chronically ill and investing more, at the margins, in improvements or plan features (such as pediatrics) that can be marketed to subscribers who are healthier on average. It also argues for weighting the plans' marketing and demarketing efforts in the same ways.

A primarily defensive posture requires steps such as the following:

- Investing in ways to contain *costs* of care to chronically ill people already enrolled as a way to keep down overall premiums while avoiding attracting more such enrollees.
- Investing in ways to meet the specific *quality* requirements of accrediting organizations and to gather the data they require on specific performance standards relating to chronically ill people, but avoiding going beyond these requirements.
- Taking care not to overinvest in costly services, new technologies, or benefits that are particularly desirable to a group of chronically ill employees and that are better than those of competing plans.
- Being careful not to outdo competitors in empaneling those types of providers of care (specialty clinics or physicians) widely known for their attractiveness to the chronically ill.
- Avoiding advertising care to chronically ill people unless there are extraordinary extenuating circumstances, such as the ability to keep an asthmatic child's health care costs low enough that they do not outweigh the advantage of enrolling an entire family.

A more aggressive posture regarding risk selection suggests further steps:

- Investing in research based on analysis of claims data and past enrollment and disenrollment patterns, as well as in focus groups and surveys, so as to determine which services, providers, plan features, and marketing and advertising approaches attract (or repel) low-cost subscribers.
- Avoiding specific health care providers favored by the chronically ill or, if it is necessary to contract with these providers for marketing purposes, using referral criteria that minimize their use.

- Discouraging the use of specific referral services favored by the chronically ill or their physicians by using unrefined review protocols that require special approvals or exceptions.
- Using primary care gatekeepers who are paid in ways that discourage referrals of chronically ill persons to specialists.
- Keeping the numbers and availability of specific types of health professionals, clinic facilities, and other resources that attract the chronically ill to a minimum, thus ensuring long waiting times.
- Identifying advertising images and slogans that give an impression the plan is designed for healthier employees rather than for the chronically ill.
- Paying physicians and hospitals in ways that pass on to them increasing amounts of risk (a practice seemingly welcomed by more and more providers across the country), as well as the problems of risk selection.

Depending on their organizational structures, health plans have different options and philosophies for underinvestment and demarketing. For example, a group- or staff-model HMO has more power to control investment in various services through its budgeting process, while a loosely organized PPO will rely on restrictive review protocols. Ironically, the integrated health plan, which has arguably the most potential to improve care to the chronically ill, also has the most options to avoid this population, because it controls the resources for care more directly. And as physicians and other providers assume more and more of the risk, they are likely to have to develop their own set of practices for demarketing to the chronically ill, a frightening thought, given providers' better knowledge of which individuals in their practice are likely to be high-cost.

However it is done, staying in the pack and demarketing produce at best weak competitive efforts to improve the quality and value of care to the chronically ill. These practices offer weak assurance of long-term improvements in care and can mean higher costs in the short run. As Medicare has documented, purchasers can end up facing higher costs for insurance and care as health plans compete to enroll the low-utilizing employees or beneficiaries and avoid those whose costs are higher.[3]

Chronically ill persons themselves face health plans that are encouraged to underinvest in their care, avoid marketing to them, construct obstacles to their complex referrals, and avoid the providers and services they have searched out as most helpful to them. If they choose to stay with these providers, it is likely to mean staying behind in higher-cost health plans while lower users opt into plans with better risk selection. In FEHBP, this can cost four times the out-of-pocket premium of other employees—thousands of dollars a year.[4]

If the computer industry were motivated to compete the way health plans compete, they would avoid investment in and marketing to the really big users of computing for fear they could not get a fair price.

PREMIUM ADJUSTORS AND DEMARKETING

Frustrated policymakers and insurance consultants sometimes downplay the importance of risk selection, saying it is not a great problem in "mature markets," where large managed care plans dominate the landscape, or that it is a transitional problem that will balance out over time in any system. The evidence, however, is more discouraging. For example, the variations in benefit value and premiums of Blue Cross's high and low options in the FEHBP mentioned above remain roughly the same today, some 6 years later. The risk selection has not proved to be transitional. As for maturity, the FEHBP has existed for more than 35 years.

Our greatest hope for correcting the risk selection problem that causes plans to demarket to chronically ill persons has been thought to be a premium adjustor, that is, a formula by which plans receive premium payments adjusted to take account of the extent of the favorable or adverse selection they experience. If a premium adjustor produced a fair premium for people who use a lot of health care, persons with chronic illnesses would become highly desirable subscribers to a health plan—and the providers they favor would likewise become highly desirable participating partners of the plan.

We are, in fact, a long way from having a premium adjustor good enough to facilitate constructive plan competition to invest in and market to the chronically ill. The ultimate test of an adjustor is whether it enables health plans to advertise to this population. Adjustors in use today do very little to correct for risk selection in general. Those being researched hold promise for doing a good bit more, but none promises to meet this ultimate test of allowing advertising to the chronically ill.

As described in recent literature, to neutralize a health plan's incentives to risk select, a premium adjustor must explain predictable variations in costs of potential subscribers at least as well as the health plan can predict them and use the demarketing techniques described above to enroll more of the predictably low users and fewer of the predictably high.[5]

One important effort uses information available in employers' personnel files to divide employees into subgroups whose health care utilization varies, assign a relative future cost to employees based on the subgroup to which they belong, and then adjust the premium of each plan based on how many members of each subgroup it enrolls.[6] Other researchers have used multiple factors (for example, indicators of physiologic health, self-reported general health perceptions and chronic diseases, and prior use of medical services) to divide employees into many subgroups and assign relative premium cost to each employee.[7] Still others have defined subgroups based on diagnostic information.

Some research focuses on predicting future years' costs of the entire insurance group (for example, the employees of one employer enrolled in one of the health plans offered) and claims considerable success in predicting and potentially adjusting premiums to take account of risk selection.[8]

Approaches to predicting and correcting for risk selection are not nearly as successful at predicting the variations in costs at the individual subscriber level. There seems to be some agreement among researchers that it is unusual to be able to explain as much as 10% to 12% of the total variation in costs,[9] or approximately two-thirds of the predictable variation[10] at the level of individual subscribers.

Do health plans have the motivation, opportunity, and resources to predict future costs of individuals or small subgroups better than those who use risk adjustors? Can health plans identify and market (or demarket) to prospectively higher-cost and lower-cost individuals within the subgroups for which research can set premium adjustors?

Plans clearly have the motivation and the opportunity. Limitations in adjustors currently being used in research leave a wide margin for plans to profit by risk selection.[11] Moreover, most of these research adjustors have been developed based on historical data or in situations where the plans have not been strongly motivated to outmaneuver the adjustor. Plans have easily outflanked the Medicare adjustor, and there is every reason to believe their efforts will substantially reduce the predictive power of research adjustors. Indeed, group purchasers will find themselves in something of an arms race with health plans, when and if they attempt to use risk adjustors.

Unfortunately, plans are far more motivated than those who might use risk adjustors to buy from them. In fact, few purchasers today have entered this arms race, since few are using risk adjustors as part of their efforts to manage competing health plans. The Pacific Business Group on Health, the California actuarially manageable service packages for which prices can be set. Ideally, a service package should encompass both comprehensive care and services for the specific condition. However, for some conditions, bidders might be able to set a price for specialty services only and work out agreements and separate prices with primary care providers for the remainder of the patient's care. The prices may be in the form of capitation or mixes of capitation and other forms of payment and risk bearing. Chronic conditions and the range of services and relationships of providers for them vary greatly. The packaging and pricing of services should be clinically driven, taking into account the nature and course of the condition being considered. This is another powerful reason to look to providers directly, rather than only to health plans, to shape the program and bid.

A third key element is choice. The consumer should be offered the choice of these different systems and allowed to discipline the market over time by choice. If the consumer wishes to stay in the traditional arrangement with traditional providers and plans, he or she should be allowed to do so.

Some employers as well as Medicare and Medicaid are already purchasing limited packages of health care from providers on a competitive basis. For example, large employers contract for transplants. Medicare contracts for coronary artery bypass grafts. Employers are purchasing "disease management" approaches to a variety of conditions, such as diabetes, pediatric asthma, coronary artery disease, pregnancy/childbirth, low back pain, breast cancer, stroke, depression, knee care, attention deficit disorder, congestive heart failure, adult asthma, hysterectomy, Alzheimer's dementia, and hypertension.

HealthPartners of Minnesota is considering requesting proposals from provider groups ("caresystems") for capitated payment for comprehensive services to people with specific conditions (for example, insulin-dependent diabetes). This payment would augment an ambulatory care group (ACG)–based risk adjustor in 1997.[14]

Medicare, Medicaid, and very large employers might take the following types of steps in pursuit of such arrangements:

- Request health plans and provider systems to propose global fees and capitation amounts for providing improved care to people with specific chronic conditions. The purchaser could use diagnostic groupings, such as ACGs, to determine a reasonable price, or it might supply the data to bidding plans and provider systems as a basis for their pricing.
- Request health plans and provider systems to bid on and arrange to offer all covered care to these persons or to demonstrate contractual or other agreements that permit all the covered care of the person to be clinically managed.
- Subtract the projected cost of these new condition-specific payments from the premium rates paid for other employees or beneficiaries.
- Contract with the "best value" provider systems and health plans in the community —or with the sole providers in rural communities.
- Allow chronically ill employees and beneficiaries to choose among health plans and provider systems. The choice might be made at the time of diagnosis as a point of service (POS) option or on a monthly basis as an enrollment shift. Medicare might offer the same choices to its beneficiaries who enroll in alternative health plans, as well as in the traditional Medicare program.

In order to encourage health plans and provider systems to bid on a global fee or capitation basis early in the program, purchasers might offer "risk sharing" arrangements to providers. For example, the employer might:

- Offer to share risks with plans and provider systems for all costs over a maximum for an

Managed Risk Medical Insurance Board, and the Minnesota Buyers Health Care Action Group have interesting plans to use relatively sophisticated risk adjustors for the chronically ill. But most purchasers who do use adjustors have limited themselves to the most elementary, such as age, sex, and geographic location of the subscribers. Medicare is using by far the most sophisticated risk adjustor today, and it is flawed and easily outflanked by health plans.[12] It is not clear why purchasers have been so slow to use adjustors; perhaps it is all just too complicated. But this reluctance does not augur well for the near-term development and use of practical adjustor systems.

When and if the race begins, health plans have formidable resources for attaining favorable risk selection beyond what the adjustor can correct for. Once plans are aware of premium adjustor subgroups and the premium each will carry, they can use the past claims and enrollment files as well as the focus groups and survey techniques described above to characterize their own subscribers over the years within each subgroup or across subgroups so as to identify those to whom they want to market or demarket. The data and financial resources available to the health plans for such research are much greater than those available to the researchers.

Adjustors based on subgroups will also set up a pernicious incentive for plans to identify individual current enrollees whose costs are substantially higher than the premium paid for the subgroup and look for ways to limit their investment in care to the premium amount. This approach would be similar to the common hospital practice of encouraging staff to get patients out within the days covered by a DRG payment, as though the DRG amount were a target or limit for patient stays rather than an average for costs of all patients in the DRG.

A tough-minded assessment of the purchasers' chances of using risk adjustors to win this arms race comes from Joseph P. Newhouse, who argues that "risk adjustment technology has to take major leaps forward to render these incentives insubstantial," and that "the expectation for further research is for modest improvement."[13]

Since the potential of managed care is so high for the chronically ill, and since the costs and quality problems are so great, it makes sense for employers, Medicare, and Medicaid to look for new approaches to augment whatever premium adjustors they find practical.

PURCHASING FOR PEOPLE WITH CHRONIC CONDITIONS: SOME APPROACHES

Unlike health plans, physicians and other providers of care have no ambivalence about marketing their services to patients with chronic conditions. Moreover, chronically ill persons on the whole are sophisticated consumers of such services and can be counted on to shop carefully for quality and price. If Medicare, Medicaid and very large private purchasers develop fair global prices or capitation rates to provider systems for specific chronic conditions, they facilitate the development of a market in which investing in and marketing to the chronically ill is desirable. Direct contracts between purchasers and providers for care to the chronically ill will force health plans to invest in and market to these subscribers if they are to hold on to them and to the large share of premium revenue they represent. If the system is structured well, chronically ill consumers will be educated to choose based on quality and value—and will use their relatively high level of sophistication about these matters to drive provider systems and health plans to serve them better.

The first key element of this approach is to assure that the price is right. Purchasers such as Medicare might use past claims data to set prices (as is done with DRGs), or they might ask plans and provider systems to bid on the provision of services for people with specific chronic conditions.

The second key element is to define specific chronic conditions as well as clinically and individual case or for an individual over a year or longer period of time.[15]

- Pay provider systems and plans a "blended rate" or partial capitation, for example, capitation for half and payment based on current costs for half, with the blend including a higher percentage of current costs for higher-cost patients.[16]
- Allow health plans and provider systems to limit the number of patients they will take in their initial years.

To assure quality, the purchaser's requests for proposals (RFPs) to health plans and provider systems might require management and clinical arrangements that clinicians and consumers consider critical to improved care for the person with the chronic condition. Accreditation by the National Committee on Quality Assurance (NCQA) might be used for this purpose, or Medicare might assemble experts and consumers to specify the best practices that high-value systems for patients with different chronic conditions should have and to develop performance measures for contracting with plans and provider systems. The RFPs might include:

- Possible organizational, risk sharing, and payment arrangements with providers.
- Evidence of investment of capital in improvement of services, treatment protocols, and best practices.
- Collection and submission of performance data, including preventive services, especially measures of preventive services that forestall chronic illnesses for which a capitated-rate is paid.
- Evidence that providers have needed expertise and that the ratio of types of providers to planned enrollment is adequate.
- Inclusion of providers with strong local reputations in care of the chronically ill in health plan panels—or justification for not including them.

The employers, Medicare, and Medicaid would also undertake an extraordinary effort to inform the choices of the chronically ill among health plans and provider systems so plans and provider systems that invest in improved quality could be rewarded with larger market share. This effort might include:

- Developing plan performance data based on best practices for various chronic conditions.
- Informing employees with chronic conditions how to make an objective choice in their own interest and equipping them with materials such as premium-to-benefit value comparisons, quality surveys of health plans and provider systems, and surveys of consumer satisfaction.

DIFFICULT ISSUES

A number of difficulties must be faced to facilitate competition among provider systems and health plans to manage care to the chronically ill. Three of these—and possible solutions—are listed below:

- *Some chronic conditions affect too few people to support more than one (or even one) provider system in an area, especially if the employees of only one employer are involved. Even the enrollees of one health plan are often too few to contain the critical mass needed to facilitate organization of provider systems.* The solution is for Medicare and multi-employer purchasers to take the lead. With Medicare's 37 million beneficiaries and a high incidence of chronic conditions in its population, Medicare in particular has enormous leverage in the market for services to chronically ill persons in most communities. Once a provider system is organized, smaller purchasers might buy from it. In rural areas or for rare conditions, sole provider arrangements might be negotiated with requirements comparable to the above.
- *There are many different chronic conditions, each requiring a different set of services. Even a very large employer will find it complex to issue RFPs to cover all these possibilities and review competitive bids in each.* The solution here is, again, relying on very large group purchasers, such as Medicare and purchasing alliances, to take

the lead. Large purchasers might work with agents such as the NCQA or the Foundation for Accountability to solicit providers and consumer organizations to develop RFP criteria and provider system performance measures relating to chronic conditions. The effort can begin slowly by selecting the conditions that impact employees or beneficiaries the most or provide the best local market opportunities.

- *Many patients have multiple chronic conditions.* The solution here is for purchasers to solicit proposals from provider systems, such as geriatric centers for elderly patients, that can bridge multiple diagnoses. Although such systems may not be feasible for many complex diagnoses, clinicians should drive the systems' design wherever they can be developed.

Successful purchasing for people with specific chronic conditions will involve a steep learning curve. It will take considerable time and resources. And some chronic conditions may simply not be amenable to this approach. However, every condition for which this approach is perfected will yield that much more value for purchasers' health care dollars.

This paper was funded by the Commonwealth Fund. The author thanks Lynn Etheredge for his assistance. In addition, he thanks those listed below, whose input was also important to the paper.

Those interviewed in connection with paper include Harry Cain, *Association of Blue Cross and Blue Shield Plans;* Debra Carpenter, *Blue Cross and Blue Shield of Minnesota;* Alain Enthoven, *Stanford University;* Merwyn Greenlick, *Stanford University;* George Halvorson, *Health Partners of Minnesota;* Peter Juhn, M.D., *Kaiser Health Plans;* Richard Niemiec, *Blue Cross and Blue Shield of Minnesota;* Ann L. Rabinow, *Minnesota Buyers Health Care Action Group;* James L. Rinertson, M.D., *HealthSystem Minnesota;* Joan Trauner, *Coopers and Lybrand;* and Steve Wetzel, *Buyers Health Care Action Group.*

Those whose discussion in related meetings informed this paper include Bruce Fireman, *Kaiser Health Plans;* Margaret Jordan, *Southern California Edison;* Richard Kronick, *University of California, San Diego;* John Ramey, *California Managed Risk Medical Insurance Board;* Michael Von Korff, *Group Health of Puget Sound;* and Cathy Colton, *Harvard Community Health Plan.*

ENDNOTES

1. Mark Slesinger and David Mechanic, "Challenges for Managed Competition from Chronic Illness," *Health Affairs*, Supplement, 1993.

2. The Federal Employees Health Benefits Program: Possible Strategies for Reform. Report prepared by the Congressional Research Service for the Committee on Post Office and Civil Service, U.S. House of Representatives, May 24, 1989, pp. 184-188.

3. Randall Brown et al., "The Impact of the Medicare Risk Contract Program on the Use of Services and Costs to Medicare," Mathematica Policy Research, Inc., December 3, 1992. Cited in General Accounting Office report to Congress on Medicare, September 1994.

4. The Federal Employees Health Benefits Program. CRS report for the House Committee on Post Office and Civil Service, September 1994.

5. Joseph P. Newhouse, "Patients at Risk: Health Reform and Risk Adjustment," *Health Affairs*, Spring 1994, p. 142.

6. For example, "a recently hired, single, female clerk, 23 years old, would carry with her an annual contribution of $563; a single female professional, 60 years old with 10 years on the job would bring a contribution of $1,277; and a female clerk, married with children, 40 years old with 15 years on the job, would bring a contribution of $1,529 to whichever plan she chooses." (James C. Robinson et al., "A Method for Risk Adjusting Contributions to Competing Health Insurance Plans," *INQUIRY*, Summer 1991, pp. 107-116.)

See also James C. Robinson, "A Payment Method For Health Insurance Purchasing Cooperatives," *Health Affairs*, Supplement, 1993, pp. 65-75.

7. Joseph P. Newhouse et al., "Adjusted Contribution Rates Using Objective Health Measures and Prior Utilization," *Health Care Financing Review*, Spring 1989, Vol. 10, No. 3.

See also Joseph P. Newhouse et al., "Risk Adjustment for a Childrens' Capitation Rate," *Health Care Financing Review*, Fall 1993, pp. 39-54.

8. For a recent review of this and related research, see Jinnet Fowles, Jonathan Weiner, and David Knudson, "A Comparison of Alternative Approaches to Risk Measurement," Physician Payment Review Commission, December 1994.

9. Harold S. Luft, "Potential Methods to Reduce or Eliminate Risk Selection and Its Effects," presented at a workshop entitled Risk Selection in a Reformed Marketplace, sponsored by the Robert Wood Johnson Foundation and conducted by the Alpha Center, October 6, 1994.

See also "A Comparison of Alternative Approaches to Risk Measurement," Physician Payment Review Commission, December 1994.

10. Newhouse et al., "Adjusted Contribution Rates," p. 49.

11. Newhouse et al., "Adjusted Contribution Rates," p. 49.

12. Stuart Schmid, "Geographic Variation in Medical Costs: Evidence from HMOs," DataWatch, *Health Affairs*, Spring 1995.

13. Newhouse, "Patients at Risk," p. 141.

14. The author interviewed George Halvorson, CEO of Health Partners, and Stephen Wetzel, CEO of the Minnesota Buyers Health Action Group, which is collaborating in this effort. For more on ACGs, see Barbara Starfield et al., "Ambulatory Care Groups: A Categorization of Diagnoses for Research and Management," *Health Services Research*, Vol. 26, No. 1, April 1991.

15. Slesinger and Mechanic, "Challenges for Managed Competition."

16. Newhouse, "Patients at Risk," p. 142.

ISBN 0-16-055952-9

90000

9 780160 559525