

Delivering on the Promise:

U.S. Department of Health and  
Human Services

Self-Evaluation  
**to Promote**  
**Community Living for People**  
**with Disabilities**

**Report to the President**  
**On Executive Order 13217**

(a)

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# Department of Health and Human Services

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# Chapter I

## Executive Summary

*"The Americans with Disabilities Act declared our nation's commitment to embrace citizens with disabilities and help them participate more fully in the lives of their communities. Eleven years later, we need to keep working to open the doors to independence. The President has laid out a comprehensive plan in his New Freedom Initiative. The steps we're taking today are one part of that greater plan."*

*-- Secretary Tommy G. Thompson, July 25, 2001, celebrating the 11<sup>th</sup> anniversary of the ADA and announcing the creation of the Interagency Council on Community Living*

### INTRODUCTION

The day-to-day work of the United States Department of Health and Human Services (HHS) touches the lives of every American and has special significance for Americans with disabilities. HHS provides funds and oversees critical and significant programs that serve people with disabilities of all ages. In FY 2000, total HHS expenditures for people with disabilities was \$73.5 billion. The largest of these expenditures was for Medicaid (\$43 billion). Medicare spending totaled approximately \$28 billion. The Social Services Block Grant spent \$1.8 billion, while the Substance Abuse Block Grant totaled \$1.6 billion. Another billion dollars was awarded in grants under the Older Americans Act. A total of 24 HHS programs provide services to people with disabilities.

President George W. Bush's New Freedom Initiative has imparted new direction and energy to HHS' efforts on behalf of individuals with disabilities. Promoting full access to community life is one of the major objectives of the President's Initiative. One of the specific actions taken by the President to advance this objective was the issuance of Executive Order 13217 on community-based alternatives, which called for a comprehensive assessment of existing federal policies, programs, statutes and regulations to identify barriers that impede community living and for recommended solutions. The President directed that this assessment involve broad public input.

This report, *Delivering on the Promise: HHS Self-Evaluation to Promote Community Living for People with Disabilities* is based upon an exhaustive agency self-assessment and review and analysis of comments from more than 800 individuals and organizations representing diverse interests and disabilities. The process led HHS to identify critical barriers to community-based alternatives for people with disabilities and commit to take concrete action to reduce and eliminate those barriers.

As a result of the work that has been done by HHS in response to the President's Executive Order, HHS now has, for the first time, a comprehensive policy framework to guide and coordinate the activities of the multiple HHS components involved in supporting community living for people with disabilities. For the first time, HHS will also have a formal mechanism – an Office on Disability and Community Integration – to oversee implementation of HHS-wide policy and activities concerning community supports. The establishment of a comprehensive HHS policy and the creation of a formal mechanism to oversee policy implementation in this area is an historic turning point for HHS.

*Delivering on the Promise* is divided into three chapters. This chapter includes a brief description of the Executive Order and the methodology used to conduct the HHS self-assessment, and summarizes the actions that HHS will pursue to further promote community integration. Chapter II describes HHS components and the financing and structure of community supports, detailing the key HHS programs that provide them. In addition, Chapter II highlights the critical work of HHS to promote community integration, including efforts over the past year to implement the New Freedom Initiative. Chapter III sets forth the concrete actions that HHS will pursue to further promote community integration and summarizes the barriers future activities will address.

## **EXECUTIVE ORDER ON COMMUNITY-BASED ALTERNATIVES**

On June 18, 2001, President Bush signed Executive Order No. 13217, "Community-Based Alternatives for Individuals with Disabilities." The Order calls upon the federal government to assist states and localities to implement swiftly the decision of the United States Supreme Court in *Olmstead v. L.C.*<sup>1</sup>, stating: "The United States is committed to community-based alternatives for individuals with disabilities and recognizes that such services advance the best interests of the United States."

Executive Order 13217 is an important component of President Bush's New Freedom Initiative. It is a milestone because it marks the first time since enactment of the Americans with Disabilities Act (ADA) that the Administration has directed federal agencies to take specific actions to eliminate the unjustified segregation of individuals with disabilities in institutions.

The President's charge to federal agencies in the New Freedom Initiative and in Executive Order 13217 has special relevance to the work of HHS. As the agency that

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<sup>1</sup> In *Olmstead v. L.C.*, 527 U.S. 581 (1999), the Supreme Court held that the unnecessary institutionalization of qualified individuals with disabilities in institutions is a form of discrimination prohibited by the ADA. The Court held that states are required to provide community-based services for persons with disabilities who would otherwise be entitled to institutional services when: (a) treatment professionals reasonably determine that such placement is appropriate; (b) the affected persons do not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving state-supported disability services.

administers Medicaid, the largest public program supporting health care, HHS has a critical role to play in achieving community integration for people with disabilities. Accordingly, the Order designated HHS as the lead agency with responsibility for coordinating the federal response to the Executive Order.

## **HHS SELF-ASSESSMENT METHODOLOGY AND BARRIER IDENTIFICATION**

HHS undertook a systematic self-evaluation process pursuant to Executive Order 13217, which featured:

- Review by each HHS component of all policies, programs, statutes and regulations.
- Written analysis by all components of barriers to community integration and potential solutions.
- Review of existing studies identifying barriers to community integration.
- Creation of an Interagency Council on Community Living to coordinate all federal agency evaluations and public input.
- Collection of public input, through the combined effort of ten federal agencies spearheaded by HHS, via three specially created venues (day-long “National Listening Session”; national toll-free conference call; and formal public comment period published via notice in the Federal Register).
- Formation of “Solutions Subgroups,” made up of representatives of various HHS components, to review and analyze solutions offered via public input and through component self-assessments.

This self-evaluation process revealed five major types of barriers to community living for people with disabilities: (1) imbalance in system structure and finance; (2) lack of responsiveness of services to meet individual needs; (3) need for greater assistance to families and informal caregivers; (4) fragmentation and lack of coordination; and (5) need for increased accountability and legal compliance.

## **BLUEPRINT FOR DELIVERING ON THE PROMISE**

To address these barriers, HHS has developed a comprehensive policy framework featuring seven basic types of action:

- **Infrastructure** - HHS will build an enhanced infrastructure within the Department to promote community alternatives for people with disabilities through the establishment of the Office on Disability and Community Integration and other management initiatives.
- **Collaboration** – HHS will support an unprecedented level of collaboration within HHS and among federal agencies that provide critical supports and services to people with disabilities.

- **Regulatory and Legislative Reform** – HHS will propose system reforms to reduce institutional bias by eliminating administrative inefficiencies, reducing fragmentation and increasing services.
- **Stakeholder Participation** – HHS will ensure on-going input of key stakeholders in system reform efforts through the Medicaid Reform Task Force and other workgroups.
- **Innovative Demonstrations** – HHS will test new models of community-based services delivery through demonstrations to improve supports to family caregivers, and improve access to community-based treatment for adults and children with mental illness.
- **Mediation of Complaints** – HHS will collaborate with the Department of Justice to enhance alternative dispute resolution options available to individuals who file ADA complaints with HHS that allege non-compliance with *Olmstead*.
- **Technical Assistance** – HHS will develop more and better technical assistance to states to promote community-based care and compliance with *Olmstead*.

Some of the specific actions included in HHS' blueprint for improving access to community living for people with disabilities are highlighted in each category below. A complete list of such actions is provided in Chapter III.

## I. **Developing a Coherent, Cost-Effective System of Administration and Finance**

### Eliminating Institutional Bias in HHS Programs

- HHS will seek greater flexibility for states and a broader set of options for people with disabilities under Medicaid home and community-based services (HCBS) waivers. HHS will promote enhanced opportunities for people of all ages who have disabilities to participate in their communities and exercise meaningful choice and control over services.
- HHS will establish an advisory committee that will recommend reforms in HHS programs to remove barriers and promote community living on the part of people with disabilities. The committee will include substantial representation by individuals with disabilities, family members of individuals with disabilities, advocacy organizations, and providers, as well as state and local government representatives.
- HHS will offer "Phase II" of the "Real Choice System Change" grants, which generated enormous interest from states, attracting approximately \$240 million in requests from states to fund systems change. Additional funds will help states make



critical progress towards systemic reforms enhancing home and community-based services.

### Services for Persons with Mental Illness

- HHS will develop and implement strategies to improve access to HCBS waiver and non-waiver services for adults and children with mental illness or emotional disturbances, or co-occurring mental illness and substance abuse or other disorders.
- HHS will also propose statutory improvements to create a ten-year HCBS demonstration as an alternative to Medicaid-funded psychiatric residential treatment centers. The demonstration would allow states to set up home and community-based alternatives for children who would typically be served in psychiatric residential treatment facilities.

### Improving Availability and Capability of Direct Care Workers

- HHS will initiate, together with a limited number of volunteer states, a national demonstration designed to address workforce shortages of community service direct care workers. Participating states would develop options for workers to purchase affordable group health coverage through the state health insurance system or similar organized insurance group.
- HHS will undertake an initiative to (a) mobilize and make available to states a coherent body of information about methods to address worker shortage issues, (b) research significant issues, and (c) partner with foundations, other private sector organizations, the Department of Labor, and other agencies to formulate a comprehensive approach to the worker shortage issue.

## **II. Assistance to Families and Informal Caregivers**

- HHS will propose a demonstration project to allow states to include respite (temporary care that offers support to family caregivers) as a Medicaid service. Unrelieved caregiver burden is a major contributing factor to institutionalization of individuals with disabilities. Respite care is the service most often requested by families in an effort to keep family members with disabilities at home.
- HHS will provide model waivers through the Medicaid program that will provide states with greater flexibility to support families within cost-neutral budgets.

## **III. Improving Coordination and Reducing Fragmentation**

- HHS will establish an Office on Disability and Community Integration. The Office on Disability and Community Integration will serve as the focal point within the

Department for disability issues including the coordination of disability science, policy, programs and special initiatives within the Department and with other federal agencies. The Office on Disability and Community Integration will be led by a senior-level HHS official.

- HHS proposes that the President publicly and permanently establish the Interagency Council on Community Living and set forth its mission and charge. Membership would include all agencies listed on the Executive Order, as well as the Internal Revenue Service (IRS), Department of Transportation, and others as appropriate. Designated members would be Secretaries, agency heads, or the equivalent. In addition, staff would be assigned to meet regularly to conduct the ongoing interagency work.

#### **IV. Ensuring Accountability and Fulfillment of Legal Obligations**

- HHS and the Department of Justice (DOJ) will develop a pilot program to use DOJ's alternative dispute resolution program to resolve individual complaints filed with HHS that allege violations of the ADA Title II integration regulation as interpreted in the *Olmstead* decision.
- HHS will work with states and people with disabilities to improve the quality of home and community-based services, and will engage a national contractor to help states implement effective quality improvement strategies.

#### **CONCLUSION**

In the aftermath of the tragic events of September 11, freedom has taken on a new meaning for all Americans. However, for Americans with disabilities, freedom has always held a special meaning – the freedom to live as independently as possible. As one of the individuals testified at the National Listening Session several days before the September 11 tragedy:

*I developed multiple sclerosis when I was in my 40's and became a disabled person. I lost my wife, my ability to work, my house. I lost everything. Now I live at a poverty level on Social Security disability. I live in an elderly housing project in a 500 square foot apartment. But for that I am thankful. I look around me and I see homeless people, I see people living in institutions, nursing homes. That makes me feel thankful for what I have. But I'm very afraid. I have a degenerative disease. It gets worse and it only goes in one direction. And I fear that if I can't have attendant care when I need it in my home, I will be institutionalized. And what I will lose, then, is the last thing that I have. It's my freedom.*

Consumer, September 5, 2001  
National Listening Session  
sponsored by the Interagency Council  
on Community Living

*Delivering on the Promise* makes clear that HHS is committed to promoting freedom for individuals with disabilities by tearing down the barriers that impede opportunities for community living.

## Chapter II

# Structure and Funding of HHS Services for Individuals with Disabilities and Barriers to Community Integration

### INTRODUCTION

In the two years following the *Olmstead* decision, HHS, in collaboration with states and other partners, has worked to promote and support the community integration of individuals with disabilities. In particular, since the President announced the New Freedom Initiative and under Secretary Thompson's leadership, HHS has worked vigorously to build and enhance programs that provide people with disabilities with the tools they need to live the lives of their choosing. With an eye on community integration, HHS has awarded or announced the availability of more than \$100 million in grants in the past year for programs in support of state long-term support systems, personal assistance services, family caregiver support, and community-based care for people with mental illness and prevention of secondary conditions, among others. The Department has also sponsored national conferences on independent living, and has supported state coalitions formed to promote community integration, including coalitions on community-based care for people with mental illness. Further, the Department has in the last year launched a Surgeon General's initiative on health disparities and mental retardation, and sponsored a national teleconference on how HUD's Section 8 vouchers can be used to address the critical shortage of accessible, affordable housing for people with disabilities, to name just a few efforts. (A detailed timeline of HHS activities implementing the New Freedom Initiative is set forth below on this page and following pages.)

## A Year of New Freedom

Since President Bush announced the New Freedom Initiative in February 2001, the Department of Health and Human Services has supported a number of efforts to enhance and improve community integration for people with disabilities. Highlights of a few of these efforts follow:

### February

#### HHS Community Integration Activities In 2001

**February 15, 2001 - \$113 Million to States for Caregiver Support Programs:** HHS announced the release of \$113 million in grants to states under the new National Family Caregiver Support Program, which helps family members provide care for the elderly at home. The grants will be used by states to run programs that provide critical support, including home and community-based services, to help families maintain their caregiver roles.

**February 25, 2001 - \$50,000 per state for Community Integration "Starter Grants":** HHS announced the availability of \$50,000 "Starter Grants" to each state and territory on request. The grants were designed to pay for the development of public-private partnerships, including consumer task forces, to advise on the use of federal grants to develop systems to improve community-based services for people with disabilities. Fifty-four of 56 states and territories applied for and received a grant.

This Chapter describes HHS' activities affecting individuals with disabilities, and discusses HHS' leadership in community integration efforts. The chapter also provides the context for HHS' self-evaluation by explaining the funding of services for individuals with disabilities and the structure within HHS that supports these and other services.

## HHS: One Department Working to Promote Community Integration

### OVERVIEW OF HHS PROGRAMS

HHS components are engaged in a variety of activities to facilitate the provision of health and human services programs utilized by individuals with disabilities. (A detailed description of HHS components, including key programs that serve individuals with disabilities, is included in Appendix C.) HHS agencies administer some programs directly, as in the case of Medicare, a health insurance program primarily providing acute care benefits to individuals over 65 and individuals with disabilities. HHS agencies also administer programs jointly with states and localities, such as Medicaid, a means-tested program that provides both acute and long-term benefits to certain categorical groups of individuals. Both Medicare & Medicaid are administered by the Centers for Medicare & Medicaid Services (CMS)(formerly the Health Care Financing Administration, or "HCFA").

HHS is a direct provider of health services for many American Indian and Alaska Native individuals through the Indian Health Service (IHS). In addition, HHS components fund health and human services programs provided by states, localities, tribal governments and other providers, such as the Administration on Aging's (AoA) funding of supportive services for older individuals and their families, administered

### March

**March 2001 - \$20,000 per State to Develop Coalitions on Community-Based Care for Persons with Mental Illness:** SAMHSA announced the availability of grants to support an initiative to develop state coalitions to promote community-based care for persons with mental illness. As of June 2001, 43 states received awards to assist them in developing and enhancing state coalitions addressing the *Olmstead* decision. The role of the National Coalition is to provide technical assistance to state coalitions on establishing guidelines and recommendations, identifying models, best practices and technical assistance resources, and disseminating information on *Olmstead* implementation and effective community integration plans.

**March 26 and 27, 2001 – National Blueprint for Addressing Mental Health Discrimination and Stigma:** SAMHSA sponsored "Spring to Action: A National Mental Health Symposium to Address Discrimination and Stigma." With more than 400 mental health experts and consumers attending, a blueprint for action was developed that states and local communities can use to address discrimination and the effects of stigma on lives of people with mental illness by fostering

### April

**April 2001 – New, More Flexible Eligibility Rule in Medicaid:** A new rule went into effect allowing states greater flexibility in determining Medicaid eligibility and permitting states to disregard portions of an applicant's income, such as income necessary to pay for essentials such as food and housing. Under previous rules, people in institutions could qualify for Medicaid coverage at much higher income levels than if they lived in the community, creating an "institutional bias."

through State Units on Aging, Area Agencies on Aging, tribal organizations and local service providers. The Substance Abuse and Mental Health Services Administration (SAMHSA) provides funding for a variety of activities and services regarding the needs of individuals with mental disabilities and substance abuse disorders including strategic analysis, research, data collection and review and consumer empowerment. The Centers for Disease Control and Prevention (CDC) Disability and Health Branch also funds state projects focusing specifically on promoting the health, well-being and participation of people with disabilities.

Other HHS-funded programs include primary health care programs funded by the Health Resources and Services Administration (HRSA); IHS funding of health facilities operated by Indian tribes; Temporary Assistance for Needy Families (TANF), Head Start and other child and family services funded by the Administration for Children and Families (ACF). In addition, ACF's Administration on Developmental Disabilities (ADD) supports Developmental Disabilities Councils in each state to assist in establishing a comprehensive system for meeting the needs of persons with developmental disabilities, and a Protection and Advocacy program in each state to protect the rights of such individuals.

Many HHS components provide technical assistance to states, service providers, and consumers of health and human services, such as the assistance and resource information provided to state offices of minority health and minority community groups by the Office of Minority Health (OMH). Other components involved in technical assistance activities include the Office of the Assistant Secretary for Planning and Evaluation (ASPE), AoA, ACF, CMS, SAMHSA and the Office for Civil Rights (OCR).

HHS components engaged in research activities or clinical studies include the Agency for Healthcare Research and Quality (AHRQ), the Food and Drug Administration (FDA), the National Institutes of Health (NIH), the Centers for Disease

May

**May 24-25, 2001 – Four New Grant Initiatives Announced at National Conference on Community Integration:** CMS hosted a national conference to promote more integrated, community living for persons of all ages with disabilities. At the conference, four new grant initiatives, collectively entitled "Systems Change Grants for Community Living," were formally announced. More than 500 participants, including state and federal representatives, advocates and consumers, shared information and ideas in the common goal of reform of community long-term support systems.

June

**June 2001 – National Conference Highlighting Pilot Programs for Consumer-Directed Care:** ASPE sponsored a national conference, entitled "Independent Choices," in conjunction with the Robert Wood Johnson Foundation and AARP to highlight pilot programs for consumer-directed care.

**June 2001 – Health Disparities and Mental Retardation Initiative:** HHS launched a Surgeon General's Initiative on Health Disparities and Mental Retardation to identify critical challenges and develop a national action plan to promote the health of individuals with mental retardation so that such individuals can live, go to school and work in their communities. Elements of the initiative include: a dedicated Web site; a Surgeon General's Listening Session on Health Disparities and Mental Retardation on October 10, 2001; a national conference on December 5-6, 2001, in Washington, D.C.; and products that will include a national action plan, a report on the proceedings of the conference, and a monograph describing models of existing programs providing health care services to individuals with mental retardation.

Control and Prevention (CDC) and the IHS. ASPE is responsible for the development, coordination, research and evaluation of HHS policies and programs that facilitate the long-term care for and community integration of individuals with disabilities. In addition, many HHS components participate in policy development and evaluation affecting individuals with disabilities, particularly with respect to specific populations or programs that are within the purview of the components' work.

Other components are involved in ensuring compliance with legal mandates inside and outside of HHS. The Office for Civil Rights (OCR) is charged with ensuring compliance with civil rights laws that prohibit discrimination on the basis of disability in HHS federally conducted and federally assisted programs, and is responsible for ensuring that state and local government health and social service programs comply with the ADA. The Office of Inspector General (OIG) evaluates, audits and investigates HHS programs and grantees to increase program efficiency and effectiveness and to eliminate fraud, waste and abuse. Still other HHS components provide support for internal departmental functions, such as the advice on HHS information technology and financial management matters provided by the Office of the Assistant Secretary for Budget, Technology and Finance (ASBTF) and the human resources services provided by the Program Support Center (PSC). Finally, HHS maintains an ongoing relationship with states, localities and tribal governments through the Office of Intergovernmental Affairs (IGA) and provides information to the public through the Office of the Assistant Secretary for Public Affairs (ASPA).

Most HHS programs, including those designed specifically around the needs of individuals with disabilities, are not focused exclusively or primarily on community integration. For example, HHS' major health and long-term care service programs,

June	July
<p><b>June 28, 2001 - \$8 Million in Alzheimer's Disease Demonstration Grants:</b> HHS announced the award of more than \$8 million in grants to 25 states to develop effective models of care for people with Alzheimer's disease and their families. The Alzheimer's Disease Demonstration Grants to States Program, administered by AoA, seeks to expand the availability of diagnostic and support services for people with Alzheimer's disease, their families and caregivers, as well as to improve the responsiveness of the home- and community-based care system to people with dementia.</p>	<p><b>July 11-13, 2001 – National <i>Olmstead</i> Policy Workshop:</b> AHRQ held a national workshop for state and local policymakers entitled “Beyond <i>Olmstead</i>: Making Community Based Services Work for All Persons with Disabilities.” The workshop provided participants with tools to improve their ability to work collaboratively with consumers, providers, advocates and others on accurately assessing consumer needs and planning for successful transitions from institutions or increasing the types and level of support for persons already living in the community.</p> <p><b>July 16, 2001 – Section 8 Vouchers National Teleconference:</b> OCR and HUD sponsored a toll-free, nationwide conference call on “Understanding HUD’s Section 8 Vouchers.” The conference call, which attracted 681 participants, was designed to assist states, consumers and others involved in <i>Olmstead</i> implementation with information that can help address the critical shortage of accessible, affordable rental housing for people with disabilities, best practices for maximizing choice and consumer control, and strategies for expanding access to Section 8 vouchers for people with disabilities.</p>

Medicaid and Medicare, do not focus exclusively on community integration for people with disabilities. However, other programs and the federal statutes that authorize them do reflect as part of their mandate the principle of community integration and access to community-based alternatives. One of ADD's missions is to enhance opportunities for community living for people with developmental disabilities, and this mission is reflected in the leadership shown by many state Developmental Disability Councils and Protection and Advocacy organizations in ensuring that community-based services are provided to people with disabilities. AoA's statutory mandate under the Older Americans Act is focused on helping older people remain independent in their homes and communities through the provision of supportive services such as meals-on-wheels, in-home support services, transportation services and ombudsmen services. More than 13 percent of enrollment slots in ACF's Head Start program are utilized by children with disabilities, in accordance with the Head Start Act requirement that at least 10 percent of the Head Start enrollment slots be available for this population. In addition, ACF provides funding for training, technical assistance and information dissemination activities regarding the needs of individuals with disabilities in a variety of ACF programs, including Head Start, child care and TANF.

## July

**July 25, 2001 – Creation of Interagency Council on Community Living:** Secretary Thompson convened representatives from seven federal agencies to celebrate the 11<sup>th</sup> anniversary of the ADA. At an event in the HHS Great Hall, at which Department of Labor Secretary Elaine Chao, Department of Education Secretary Rod Paige, and other high-ranking officials participated, Secretary Thompson announced the creation of the Interagency Council on Community Living. Following the event, HHS' Deputy Secretary Claude Allen convened the council's first meeting.

**July 25, 2001 - \$9 Million in Grants to Support Employment of People with Disabilities:** HHS announced \$9 million in grants to 18 states to help people with disabilities to become and stay competitively employed. The grants enable states to increase services and supports to workers and help others return to work without fear of losing health coverage. States can use the funds to build systems that provide personal assistance and supports, to reach out to people with disabilities, to train staff in new employment possibilities and to improve transportation or other support programs.

## August

**August 5-7, 2001 – Conference on Community-Based Care for Persons with Mental Illness:** SAMHSA convened the 2001 National Technical Assistance Annual Mental Health Block Grant Conference for state mental health planners. The conference, "Partnerships for Integration: Strategies for Serving Individuals and Families," included topics on the *Olmstead* decision and National and State Coalitions to Promote Community-Based Care for Persons with Mental Illness.

**August 13, 2001 – Promising Practices for Children with Serious Emotional Disturbances:** SAMHSA released three new volumes of promising practices for families, communities and caregivers to help build exemplary systems of care for children with serious emotional disturbances and their families.

**August 23-24, 2001 – Product Standards and People with Disabilities:** FDA undertook an initiative to develop and revise guidelines to address the needs of older persons and persons with disabilities when developing standards.



# The Need for Community-Based Alternatives

## SERVICES AND SUPPORTS NEEDED BY INDIVIDUALS WITH DISABILITIES

There are approximately 54 million individuals with disabilities in the United States. The General Accounting Office (GAO) recently estimated that at least 1.8 million of these individuals are being served in institutional settings, including 1.6 million individuals in nursing facilities, 106,000 individuals in institutions for people with mental retardation and developmental disabilities, and 57,000 individuals in state and local facilities for individuals with mental illness.<sup>2</sup> Approximately 52 million individuals with disabilities reside in the community. The GAO estimated that an additional 2 million individuals are at risk of entering an institution in order to receive care.<sup>3</sup>

Many people with disabilities require help with the activities of daily living, such as dressing, eating, transferring, bathing, and toileting. Other individuals, particularly those with developmental or psychiatric disorders, may be physically capable of carrying out these tasks, but may need supervision, instruction or support to function independently. When physical or supervisory assistance is provided, tasks may include “personal assistance services,” such as assistance with getting out of bed, dressed and fed, home health, homemaker and chore services, medication management, assistive devices, meals on wheels and respite services and other relief provided to families and other natural caregivers.

<sup>2</sup> Long-Term Care: Implications of Supreme Court's *Olmstead* Decision Are Still Unfolding, United States General Accounting Office, Testimony of Kathryn G. Allen before U.S. Senate Special Committee on Aging at 6-7 (Sept. 24, 2001) (GAO Testimony)

<sup>3</sup> GAO Testimony at 7.

## September

**September 6-7, 2001 – National Conference on Family Caregiver Support Program:** The Assistant Secretary for Aging of HHS hosted “The National Family Caregiver Support Program: From Enactment to Action” conference to highlight the exciting new federal program that provides grants to states to serve the family caregivers of the growing population of older persons. More than 700 representatives of the nationwide network of state and area agencies on aging, tribal organizations and service providers attended the conference.

**September 10-12, 2001 – Promoting Community Integration via PACE:** CMS unveiled a new format to help states adopt Program for All-Inclusive Care for the Elderly (PACE). CMS hosted a conference to enable the sharing of information as to how states may adopt PACE to promote community living. In November 2001 CMS approved the nation’s first application for permanent provider status under Medicaid and Medicare.

**September 24-26, 2001 – Training for State *Olmstead* Coordinators:** SAMHSA held the first annual Training Institute for State Mental Health *Olmstead* Coordinators. Technical assistance on coalition-building strategies to promote consumer and family involvement in *Olmstead*-related planning and incorporation of evidence-based practices was provided to participants.

**September 25, 2001 - \$5 million in Native American Caregiver Support Program Grants:** HHS announced nearly \$5 million in grants to 119 tribal organizations to implement the new Native American Caregiver Support Program. Grants were awarded to 110 tribal organizations to provide families of Native American and Native Hawaiian elders with access to information, respite care, counseling, training and supplemental services to help them meet their real-life caregiving challenges. In addition, nine tribal organizations each received \$100,000 demonstration grants to develop and evaluate model caregiver support programs.

Currently, approximately one quarter of individuals with disabilities (approximately 12.6 million of the 54 million people with disabilities) require help with the activities of daily living. About 42 percent of these individuals are under 65, and approximately 500,000 are children. Approximately 58 percent of individuals who need help with the activities of daily living are age 65 or older. The number of individuals who require long-term care is expected to increase within the next several years, as "baby boomers" age.<sup>4</sup>

The vast majority of people with disabilities who need direct assistance (10.3 million or 82 percent) live in the community. Fifty-five percent of this population is elderly with the remainder under age 65. The remaining individuals (approximately 18 percent) live in institutions, including nursing homes, intermediate-care facilities for the mentally retarded, other facilities for the mentally retarded, and facilities for the mentally ill. For most individuals with disabilities, institutional placement is rarely considered acceptable unless there are no other alternatives. For people living in all locations, professionals (such as nurses, doctors, physical therapists, and speech therapists) provide essential services. Those professionals, however, provide less service overall than such direct service workers as personal attendants, homemakers, transportation workers. Outside of institutions, the majority of care is provided by family and informal caregivers. Women occupy the majority of paid direct service caregiver positions, and minority women are disproportionately represented among these low-wage occupations.

Poverty is much higher among people who have a disability, especially those under age 65, compared with the general population. Among persons living in the community, approximately 38 percent of nonelderly adults and 24 percent of the elderly with long-term care needs lived below poverty in 1990.

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<sup>4</sup> GAO Testimony at 7-8.

## September

**September 28, 2001 - \$64 Million for States to Undertake Systems Change for Community Living:** HHS announced approximately \$64 million in new grants to 37 states and one territory to develop systems to change community-based reform programs for people with disabilities or long-term illnesses. The funds are part of four grant programs:

- \$40.8 million in "Real Choice Systems Change" grants to help states design and implement effective and enduring improvements in community long-term support systems to enable children and adults with disabilities or long-term illnesses to live and participate in their communities;
- \$7.6 million in "Community-Integrated Personal Assistance Services and Supports" grants to support states' efforts to improve personal assistance services that are consumer-directed or offer maximum individual control;
- \$11.1 million in "Nursing Facility Transitions" grants to help states transition eligible individuals from nursing facilities to the community; and
- \$4.9 million in "National Technical Assistance Exchange for Community Living" grants to provide technical assistance, training and information to states, consumers, families and other agencies and organizations.

## WHO PAYS: THE FINANCING OF SERVICES AND SUPPORTS FOR PEOPLE WITH DISABILITIES

A preponderance of assistance for people with disabilities is provided directly by families, friends, and neighbors. Medicaid is the largest contributor of public funds, providing \$43 billion. Medicare provided \$28 billion for such assistance. Private insurance is estimated to contribute \$6 billion. In addition, \$34 billion is paid as out-of-pocket expenses by people with disabilities or long-term illnesses and their families.

## HHS EXPENDITURES REGARDING INDIVIDUALS WITH DISABILITIES

In Fiscal Year 2000, total HHS expenditures for people with disabilities were \$73.5 billion. The largest of these expenditures were for Medicaid (\$43 billion), Medicare (\$28 billion), the Social Services Block Grant (\$1.8 billion), the Substance Abuse Block Grant (\$1.6 billion), and the Older Americans Act Grants (\$1 billion). A total of 24 HHS programs provide significant services to people with disabilities who reside in or are returning to community-based settings.

Despite the fact that public programs pay less than 25 percent of the cost of long-term support and services, the dollar value of such expenses is considerable. For example, expenses for elderly and people with disabilities represent approximately 71 percent of the national Medicaid budget. Moreover, Medicaid represents one of the largest items in state budgets.

## October

**October 1, 2001 – Children with Special Health Care Needs:** National Child Health Day focused on the theme: *All Aboard the 2010 Express: A 10-Year Action Plan to Achieve Community-Based Service Systems for Children and Youth with Special Health Care Needs and their Families*. HHS mailed more than 5,000 kits to states and communities to help them plan events around this theme. On November 19, 2001, a national event in Broward County, Fla., for Child Health Day showcased the efforts of one Community of Excellence to put in place a family-centered, comprehensive, coordinated system of care for children and youth with special health care needs.

**October 1, 2001 – \$6 Million for Innovative Approaches to Family Caregiver Support Program Grants:** HHS announced, as part of the National Family Caregiver Support Program, approximately \$6 million in grants for 34 projects to develop innovative approaches to assist families and informal caregivers of older persons as well as grandparents and older relatives who are caregivers of children. Grants were awarded to state and area agencies on aging, nonprofit community service providers, institutions of higher learning and national organizations with demonstrated expertise in aging and caregiving issues. The five priority areas that grants focus on are: systems development; service components; linkages to special populations and communities; field-initiated demonstrations to develop and test new approaches to support caregivers; and national projects that enhance the development of caregiver programs.

**October 22, 2001 – \$5 Million to Enhance Community Living through Prevention of Secondary Conditions:** HHS announced the availability of \$5 million in competitive funds to develop and enhance the capacity of states to address the health and wellness of people with disabilities to prevent secondary conditions. These awards will enable states to enhance access for people with disabilities to preventative health and social programs, increase participation in community services and enhance independent living through elimination of environmental barriers.

## MEDICAID FUNDING OF HOME AND COMMUNITY-BASED SERVICES

Medicaid historically has financed care delivered in nursing homes, facilities for individuals with mental retardation and developmental disabilities and other institutional settings. Indeed, in fiscal year 2000, Medicaid spent approximately \$49.5 billion dollars in these facilities.<sup>5</sup> Over the past several years, however, the proportion of Medicaid spending directed to home and community-based care has increased. In fiscal year 1990, federal and state Medicaid spending for home and community-based care comprised approximately 13.7 percent (\$3.9 billion out of a total \$29.5 billion spent in both institutions and community settings) of long-term care spending. By fiscal year 2000, federal and state Medicaid spending comprised approximately 27 percent (\$18 billion out of a total \$68 billion spent in both institutions and community settings) of monies expended on long-term care.<sup>6</sup>

Moreover, it is expected that demand for home and community-based services will increase, since these services are generally preferred by individuals over institutional care, and since they are, on a per capita basis, generally less expensive than institutional care.

Institutions historically have played a significant role in state and national long-term support systems. Unfortunately, the historical Medicaid bias towards institutional care created an imbalance in the options available to individuals to the point where institutional placement often became the primary rather than last resort. States and the federal government have recently made progress in “re-balancing” the system. Home and community-based services as a percentage of all Medicaid long-term care spending have increased from 13.7 percent of the total in 1990 to 27 percent in 2000.

<sup>5</sup> GAO Testimony at 12, figure 3.

<sup>6</sup> GAO Testimony at 12, figure 3.

### November

**Nov. 29-Dec. 1, 2001 – Emotional Health for Persons with Mental Retardation/Developmental Disabilities:** HHS held a workshop on Emotional and Behavioral Health in Persons with Mental Retardation/Developmental Disabilities: Research Challenges and Opportunities. The workshop was designed to address key questions that arise in the inclusion of persons with mental retardation in federally funded research in the United States.

### December

**December 12 and 13, 2001 – Summit on Children with Special Health Care Needs:** A National Summit in Washington, DC, showcased community and state successes, models and best practices related to building community systems for children and youth with special health care needs. The Summit was co-sponsored by HRSA/Maternal and Child Health Bureau, Family Voices, the American Academy of Pediatrics, the March of Dimes and other organizations.

The primary means through which publicly funded home and community-based services are provided is through the Medicaid Home and Community-Based Services (HCBS) “waiver” program. HCBS waiver programs are operated at state option. States apply to the HHS Centers for Medicare & Medicaid Services (CMS); for these waivers. If the waivers are granted, CMS allows states to limit the geographical area in which services are being offered, to target services to specific populations of individuals to be served, to control the number of individuals being served, and to cap overall expenditures in the waiver program. To receive approval for a waiver, states must demonstrate that the cost of the services to be provided under a waiver (plus the cost of other state Medicaid services) is no more than what would have been spent on institutional care (plus the cost of other Medicaid services provided to individuals who are institutionalized).<sup>7</sup> This principle is referred to as the “cost effectiveness” requirement.

With the exception of Arizona, every state and the District of Columbia offer at least one HCBS waiver program. States often operate several different waivers serving different population groups. Currently, states operate approximately 260 HCBS waiver programs, including 91 programs serving individuals with mental retardation and/or developmental disabilities; 18 programs for individuals characterized as “aged” (i.e., individuals aged 65 and older); 60 programs serving individuals who are both “aged” and disabled; 40 programs for individuals with physical disabilities; 23 programs serving people with traumatic brain injuries; 17 programs for individuals with AIDS; 4 waiver programs serving people with mental illness; and 11 programs for individuals who are medically fragile and technology dependent.

In 1999, the average cost of HCBS services was approximately \$15,000 per recipient, representing a range of needs and expenditures. For example, the average cost of services for individuals with developmental disabilities was approximately \$30,000, and the average cost of services for aged and disabled individuals was approximately \$6,000. Average per capita costs for HCBS services are much lower than the average per capita costs of institutional care, although HCBS figures do not include other expenses incurred in a home or community-based setting, such as housing, meals, transportation and the costs borne by family members and other informal caregivers.<sup>8</sup>

In numerous states, many more individuals seek HCBS waiver services than there are waiver “slots” available. This imbalance of supply and demand may result in waiting lists for HCBS services. In a 1998-99 telephone survey of all 50 states and the District of Columbia, only eight states reported that they believed their waiver capacity and funding to be adequate and that they did not have waiting lists for HCBS waiver services.<sup>9</sup>

The HCBS waivers have been used most extensively for persons with developmental disabilities. As an alternative to intermediate care facilities for persons with mental retardation (ICF/MRs), the waivers have permitted states to stabilize and then reduce

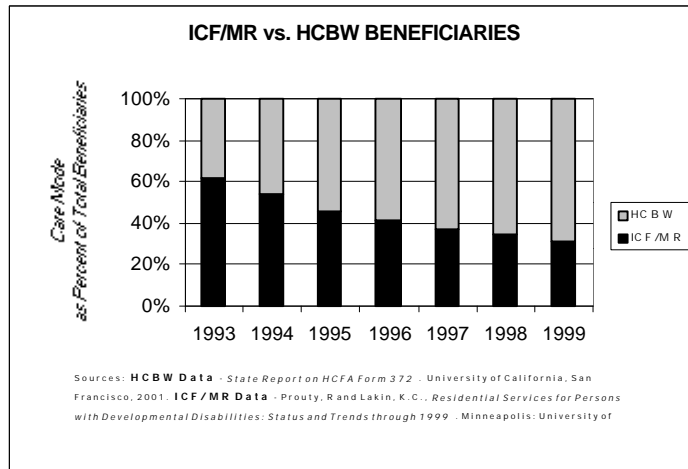
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<sup>7</sup> GAO Testimony at 12 – 13.

<sup>8</sup> GAO Testimony at 14.

<sup>9</sup> GAO Testimony at 16.

reliance on such institutions. From 1993 to 1999, the number of Medicaid-eligible people served in ICF/MRs declined from 149,000 to about 118,000. The following graph shows that ICF/MRs served 62 percent of the combined number of all such beneficiaries in 1993, and only 26 percent in 1999. The percentage served in HCBS waivers went from 38 percent to 74 percent.



In addition to the HCBS waiver program, Medicaid also funds other types of home and community-based services. States must fund home health care services for medically necessary care, including such services as nursing, home health aides, medical supplies, medical equipment and appliances suitable for use in the home. States have the option to fund personal care services, which typically include a range of services that enable people with disabilities to accomplish certain tasks that they would normally do for themselves if they did not have a disability. Personal care services include assistance with activities of daily living and may include meal preparation, housecleaning, transportation, financial and medication management.

## HHS Leadership in Promoting Community Integration

As stated above, HHS components have spearheaded numerous efforts to promote community integration and to foster voluntary compliance with the ADA and the *Olmstead* decision.

For example, **CMS** has supported states in expanding the array of choices in community-based services and supports and in increasing the proportion of total Medicaid expenditures devoted to community options. While bias towards institutional placements remains, HHS and states have significantly expanded the services and supports available to individuals with disabilities in the community.

Three services are particularly important to community living: 1. personal care services, 2. home health services, and 3. home and community-based waivers. Progress in each of these areas is outlined below.

### **Personal Care and Home Health Services**

Currently 31 states have opted to provide personal care services under their Medicaid program and all states provide home health services. Under grants to states made under the Ticket to Work and Work Incentives Improvement Act of 1999, 18 states intend to modify their personal assistance services program to more fully support the employment and community participation of individuals with disabilities.

HHS and states have also been exploring nurse delegation authority and choice within both the home health and personal care benefits to control cost and expand the pool of direct service workers.

### **Home and Community-Based Waivers**

Currently, 260 Medicaid home and community-based waivers have been approved serving more than 615,000 individuals with significant disabilities. In fiscal year 2000, states and the federal government spent \$12.3 billion on Medicaid home and community-based waivers. Since February 2001, 19 new waivers have been approved and 24 waiver amendments have been approved that will increase the availability of these services to individuals with disabilities.

### **Real Choice System Change**

In September 2001, CMS awarded Real Choice System Change grants, a \$64 million package of competitive grants to states and other organizations to help design and implement improved methods of providing supports and services to enable the full community integration of individuals who have a disability or long-term illness. CMS has also revised its Medicare payment system for home health services in order to encourage home visits and services that are more responsive to the needs of Medicare-eligible individuals.

CMS has also worked with states to approve innovative Medicaid waivers that promote community integration. These include "self-directed services" waivers that enable individuals or families to provide more direction over the services upon which they depend. They include comprehensive system reforms in a number of states that promote persons-centered planning together with flexible, integrated long-term support services that are free to follow each individual to the most appropriate and preferred setting. CMS also worked with Programs for All-Inclusive Care of the Elderly (PACE) to accommodate greater flexibility in how current models can provide the most effective community services. In November, CMS also approved the nation's first PACE application for permanent provider status (rather than a waiver) with joint Medicaid-Medicare funding.

**OCR** has played a leading role in working with states to foster voluntary compliance with the ADA's integration regulation and the *Olmstead* decision. OCR staff in 10 regions nationwide are aiding many of the approximately 40 states undertaking efforts to develop and implement the "comprehensive, effectively working plans" discussed in the *Olmstead* decision. OCR is working to voluntarily resolve administrative complaints filed with OCR that allege a violation of the ADA integration regulation. OCR is also working with expert consultants to provide on-site technical assistance to states engaged in collaborative planning efforts. With the help of these experts, OCR is developing technical assistance products to help guide states in their efforts and has conducted a specific technical assistance conference call on housing. OCR has collaborated with CMS and with other key components, including AoA, SAMHSA, ASPE and ADD to develop policy initiatives and program changes to enhance states' ability to improve access to home and community-based services and comply with the ADA. For example, OCR and other components aided CMS in developing criteria for the Real Choice System Change grants and worked closely with CMS on a series of letters to state Medicaid Directors to address *Olmstead* Implementation and Compliance issues.

Other HHS components are also involved in activities to facilitate the full integration into the community of individuals with disabilities. For example:

- **OIG, CMS, ASPE and AoA** are involved in research, evaluation and demonstration activities concerning services that promote community integration and that give individuals with disabilities more control and direction over the services they require.
- Grants from **SAMHSA** are supporting the development of community-based systems of care for people with mental illness and co-occurring substance abuse disorders, including grants in 43 states to develop and enhance state coalitions on community-based care.
- Grants from **AoA** are providing support for family caregivers, with a focus on systems development, service components, linkages to special populations and communities, field-initiated demonstrations and national projects to enhance the development of caregiver programs. The AoA also provided grants to tribal organizations to implement a Native American Caregiver Support Program.
- **CDC** has led the development and inclusion of a chapter in the "Healthy People 2010" publication dedicated specifically to the health and well-being of individuals with disabilities and has undertaken work to gather data concerning individuals with disabilities. "Healthy People 2010" presents the nation's health agenda for the next decade. For the first time, this agenda includes a specific chapter, Disability and Secondary Conditions, that contains objectives to improve the health and participation of people with disabilities. These objectives focus on areas paralleling those in this Presidential report—mental health, environmental barriers, societal participation, assistive technology, long-term care, work, and school. A soon-to-be-released report, "Disability and Secondary Conditions: A Vision for the Decade," provides guidelines for implementing activities to achieve the goal of full participation.



- **HRSA** is funding programs for children with special health care needs in accord with the Social Security Act's Maternal and Child Health Services Block Grant; funding community-based care for individuals living with or affected by HIV/AIDS; administering grant programs that support the development and delivery of health care in rural areas; training health professionals to provide care in underserved areas; and working to implement HHS' "Healthy People 2010" objective of community-based systems of services for all children in the United States with special health care needs.
- **IHS** is supporting a variety of grant projects, funded in conjunction with agencies both inside and outside HHS, that support the development, delivery and evaluation of services to American Indian and Alaska Native individuals with disabilities.
- **AHRQ** has begun to bring experts together to build a research agenda in the area of disability and conducted a national workshop to provide tools for consumers, providers, advocates, and state and local policymakers to assess consumer needs and planning for successful transitions from institutions, as well as increase the types and levels of support for persons currently living in the community.

## **Barriers Identified Through the HHS Component Self Evaluation and Public Input**

As described above, HHS has been engaged in a wide variety of efforts to promote and support the community integration of individuals with disabilities. As the self-evaluation and public input processes made clear, however, people with disabilities continue to confront barriers to full community inclusion. (A detailed discussion of the identified barriers is provided in Appendix A). These barriers cut across programs and populations. The public input regarding barriers may be broadly described and classified into the following five categories:

### **1. IMBALANCE IN SYSTEM STRUCTURE AND FINANCING**

**Medicaid:** While Medicaid is a critical program and a significant source of funding for long-term care for people with disabilities, the rules for coverage, eligibility and administration favor spending on institutional care. The public input to HHS' self-evaluation emphasized that these rules result in a "bias" towards institutional care and often result in institutionalization of children, adults and seniors even when community care is less expensive and more appropriate for the individual. Historically, categorical eligibility and coverage rules have impeded state flexibility, frequently leaving consumers without real choice and the opportunity to direct their own care. Medicaid's structure and method of financing also results in differences in the services available to different populations. Of

particular concern is the gap in home and community-based services for adults and children with mental illness and emotional disturbances.

**Medicare:** Certain Medicare rules for home health care and durable medical equipment may limit eligibility for benefits and serve as a barrier to full integration of people with disabilities into the economic and social mainstream of their communities.

**Service Gaps:** HHS components and public respondents identified a number of service gaps resulting in unmet needs of various populations, including persons with serious mental illnesses, racial and ethnic minority populations, rural populations, and children and adolescents. Additional service gaps identified by HHS components and public respondents are inadequate discharge planning and difficulties in securing timely assistance to support transitions when a person moves from one service system to another. Finally, the self-evaluation and public input process identified as a barrier the shortage of adequately trained staff to provide needed personal care services in the community.

## **2. LACK OF RESPONSIVENESS OF SERVICES TO MEET INDIVIDUAL NEEDS**

Both HHS components and public respondents agree that Medicaid reform is needed to make the program more “person-centered.” As it currently exists, dollars in the Medicaid program largely flow to specific providers to serve specific populations. This structure can serve as a barrier to individualized, comprehensive, consumer-driven services.

## **3. NEED FOR GREATER ASSISTANCE TO FAMILIES AND INFORMAL CAREGIVERS**

Family members and informal caregivers provide the vast majority of support and direct care to people with disabilities, yet they receive little direct assistance and often face tremendous financial pressures. Inadequate family and caregiver support, respite services, and workplace supports pose significant challenges to community integration for individuals with disabilities and their families.

## **4. FRAGMENTATION AND LACK OF COORDINATION**

Individuals with disabilities face barriers to community living because the right “mix” of services and supports is rarely provided in one package. Instead, individuals with disabilities, their families and caregivers frequently must put together services and supports from multiple service programs, each of which may have its own funding streams, eligibility requirements, policies, procedures and service sites. The difficulty of negotiating these programs is compounded by lack of accurate information and assistance. Fragmentation and lack of coordination exists at all levels of government -- both within individual agencies and across agencies. The lack of an agency focal point within HHS increases the challenge of adequate disability programmatic and policy coordination.

## **5. NEED FOR INCREASED ACCOUNTABILITY AND LEGAL COMPLIANCE**

There is a need for greater oversight of programs that serve people with disabilities to ensure that they are providing adequate quality of care and stronger enforcement of laws that protect the rights of people with disabilities, including a more effective mechanism for OCR to quickly resolve individual complaints. Lack of coordination among HHS components and other federal agencies also impedes effective delivery of technical assistance and guidance to states that can promote compliance with legal obligations.

The self-assessment and public input processes identified barriers to community integration and offered solutions to those barriers. The information gleaned from these processes was central to the development of this report and to the ideas discussed in the next chapter for providing services and supports that promote community-based living for individuals with disabilities.

## **Chapter III**

### **Delivering on the Promise: Actions to Address the Barriers**

This chapter is devoted to solutions or actions that are responsive to barriers identified through the HHS self-assessment process, including those identified through public input. These solutions and actions are grouped according to five major categories: (1) coherent, cost-effective structure, administration, and finance; (2) individualized, comprehensive, consumer-directed services; (3) assistance to families and community caregivers; (4) coordination and reduction of fragmentation; and (5) accountability and fulfillment of legal obligations. Some actions can be accomplished immediately or can immediately be crafted into proposed regulatory or legislative actions. Others will take more time.

Many of the ideas contributed through the public input process had obvious merit, but require additional input, study, or time for essential parties to reach agreement on the most advisable course of action. For this reason, a limited number of workgroups have been proposed to keep these ideas alive and promote their further development.

Because a number of the solutions involve cross-cutting activities among federal agencies, we have included certain solutions designed to address collaboration and coordination among federal programs. The most significant such proposed action is the creation of the Interagency Council on Community Living as a continuing, coordinating body.

Finally, HHS strongly supports the President's announced plan to establish a National Commission on Mental Health. HHS actively encourages the Commission's further consideration of the issues and solutions raised in the public input process as related to individuals with mental illness and/or substance abuse disorders, including consideration of:

- The availability and delivery of new treatments and technologies for individuals with severe mental illness and co-occurring mental and substance abuse disorders.
- Further consideration of methods by which services for children with serious emotional disturbances and adults with mental illness and co-occurring disorders may be improved.
- Flexibility of Mental Health and Substance Abuse Block Grant services.
- Development of improved community-based services and equal treatment for persons with mental illness and/or substance abuse disorders.

# I. Coherent, Cost-Effective Structure, Administration and Financing

## A. Medicaid: Eliminate Institutional Bias

### SOLUTION I.A.1: IMMEDIATE HCBS REFORM ACTION

In consultation with states and people who have a disability or long-term illness, the Centers for Medicare & Medicaid Services (CMS) will propose a coordinated package of regulatory or potential legislative improvements that would quickly reduce some of the barriers to community living and reduce institutional biases in the Medicaid program, which may include:

- (a) **Improving waiver stability:** Remove the requirement for states to seek renewal of a 1915(c) waiver unless CMS provides the state with 6 to 12 months advance notice that renewal will be required due to identified and unresolved performance problems. Cost-effectiveness formula requirements would be retained and states would continue to provide cost-effectiveness projections. Improvements to state annual performance reporting would also be included.
- (b) **Transitions from institutions:** Clarify that temporary services designed to transition individuals to a community residence are feasible in Medicaid's home and community-based services waivers, excluding room and board, but including the one-time cost of security deposits, initial furnishings, utility/telephone set-up fees and deposits, and similar one-time initial expenses within clear limits and transition criteria established by the state.
- (c) **Level of care criteria:** Clarify that the need for "active treatment" is distinct from level of care and not required in order for an individual with MR/DD to qualify for services under an HCBS waiver.
- (d) **Focus institutional services criteria:** Allow states that have tightened or would tighten institutional eligibility for hospitals or Intermediate Care Facilities for the Mentally Retarded (ICFs-MR) to do so, without simultaneously narrowing HCBS waiver eligibility, by permitting (but not requiring) the state HCBS program to include levels of care that have been in effect in the state plan on or after passage of 1915(c) of the Social Security Act.
- (e) **Targeting income/asset disregards:** Allow states to restrict the disregard of income or resources under 1902(r)(2) to HCBS waiver eligibles, rather than apply the 1902(r)(2)

income/resource disregards to an entire, current Medicaid eligibility group (such as all medically needy individuals).

- (f) **Transitions from IMDs or Correctional Facilities:** CMS will clarify methods by which states may ensure continuity of health coverage as Medicaid-eligible individuals transition from institutions within which federal financial participation for services is precluded under 1905(a)(A) and (B) of the Social Security Act (i.e., IMDs or correctional facilities) to the community, and methods by which states may address their responsibilities for eligibility determination or maintenance while eligible persons reside in such institutions.

## **BARRIERS ADDRESSED BY SOLUTION**

The above actions may be taken without major restructuring. Each action removes or reduces an impediment that currently limits the ability of states to offer effective, timely community alternatives to institutions, as described below.

**Improving waiver stability:** HCBS waivers must now be renewed every three to five years. The waivers, however, have become an essential part of state long-term care systems. For example, the waivers have helped reduce the ICF/MRs population to the point that there are more people with developmental disabilities served in HCBS waivers than in institutions. Requiring frequent waiver renewals adds administrative expense for states, creates uncertainty about the reliability of community services in the minds of consumers and families, and conveys a bias toward institutional services (that require no federal renewal) compared to community services.

**Transitions from institutions:** Individuals seeking a return to the community from institutions are faced with many one-time expenses, such as those needed to secure an apartment, ensure telephone and electricity service, etc. This action would remove uncertainty on the part of many states and make it clear that payment of room and board is not permissible, but such one time set-up expenses may be included in HCBS waivers for individuals who make the transition from an institution.

**Level of care criteria:** HCBS waivers may only serve individuals who require the level of care typically provided in a Medicaid-funded institution. Active treatment is a service that ICF/MRs are required to provide. This action would clarify that the need for active treatment is not required for HCBS waiver eligibility and that the requirement for a facility to provide active treatment is distinct from an individual's need for a particular level of care.

**Focus institutional services criteria:** States that wish to tighten institutional level of care requirements are often prevented from doing so because to do so also narrows the eligibility for HCBS waivers. In addition, States that have tightened institutional level of care are faced with the prospect of restoring, or have restored, lower levels of institutional care due to this problem. The statutory improvement proposed here would allow states to tighten eligibility for hospital and ICF/MR admissions (but not

nursing homes) by simply permitting states to set HCBS waiver eligibility at any hospital or ICF/MR level of care covered by Medicaid since the federal HCBS waiver law was enacted in 1981.

**Targeting income/asset disregards:** Many individuals cannot leave institutions because the amount of income they are permitted to retain in the community and still obtain vital Medicaid services is insufficient to pay basic room and board. In contrast, Medicaid pays for all room and board in nursing facilities, hospitals, or ICF/MRs. Section 1902(r)(2) of the Social Security Act currently permits states to address this problem in a very broad manner by allowing states to disregard state-specified income or resources (assets) in determining Medicaid eligibility. However, states must currently apply 1902(r)(2) to entire eligibility groups, such as all persons with a disability who are medically needy. This option would permit states to narrow their application of income or resource disregards under 1902(r)(2) to people who meet institutional level of care, rather than apply it to an entire Medicaid eligibility group. This option provides states with more flexibility, allows them to adopt an incremental approach to improving their state systems, and prevents states from needing to do more than they may wish to do within the constraints of tight budgets.

**Transitions from IMDs and Correctional Facilities:** While individuals retain their Medicaid eligibility during a stay in an Institution for Mental Disease (IMD) or correctional facility, states often let such eligibility lapse if the institutional stay exceeds six months. The reason for this is that federal matching funds are not available for services to individuals during their residence in such institutions. Such lapses in eligibility create significant continuity of care problems when the individuals leave the institution for the community. This is particularly true for persons with a mental illness or HIV-AIDS who require a daily regimen of medically-monitored drugs that are critical to their health and daily functioning. States are unclear both about their responsibilities under the law and the current options for ensuring continuity of care. CMS will issue clarifying guidance.

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## **SOLUTION I.A.2: MEDICAID COMMUNITY SERVICES REFORM TASK FORCE**

CMS will establish a time-limited Medicaid Community Services Reform Task Force to advise the Department on the implementation of solutions described in this report and advise CMS on other actions that may be advisable to remove barriers and promote community living on the part of people with a disability. The Task Force will include representatives of all age and target groups within the disability community as well as representatives from key national, state and local organizations and government associations. Among its responsibilities the Task Force will consider issues related to:

- Options for improvement of home health, personal assistance services, personal emergency response systems, and other state plan services critical to health and community living;

- Supporting family members as critical caregivers and evaluating and identifying areas or conditions in which payment to family caregivers for supportive services to spouses and minor children may be prudent and cost-effective;
- Improving methods for coordinating the legitimate roles played by the single state Medicaid agency, other state-level agencies responsible for services to particular target groups, and the use of local, public administering agencies for Medicaid and related long-term support services, including agencies serving as one-stop shopping entry points into the system;
- Improving methods of alternative contracting for services employing methods that promote best-value and optimum consumer direction;
- Improving methods to make use of advances in service delivery that increase user self-direction, independence, and maintenance or development of personal supports, including person-centered planning, peer mentoring, support coordination, individualized budgeting or service direction, and agents that support an individual in managing finances and meeting legal requirements;
- Other needed reforms to promote productive employment and community participation; and
- Coordinating Medicaid and other federal programs to achieve optimum efficiency to such an extent that people with a disability will experience a community system that is as seamless, understandable, and as coherent as possible.

#### **BARRIER ADDRESSED BY SOLUTION**

Since institutional bias is embedded in the structure of the Medicaid program itself and will require legislative reform, care must be taken to fully develop options and weigh alternatives. The appointment of a Task Force with broad representation of stakeholders, including consumers, will ensure the development of practical, cost-effective solutions with high potential for enactment.

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#### **SOLUTION I.A.3: SERVICES FOR PERSONS WITH MENTAL ILLNESS**

HHS will develop and implement strategies to improve access to HCBS waiver and non-waiver services for adults and children with mental illness or emotional disturbances, or co-occurring mental illness and substance abuse or other disorders. Specifically, CMS will issue technical assistance and guidance to improve state understanding of existing options under Medicaid waivers (including section 1115 and Section 1915(c) waivers) for providing community-based services to children with an emotional disturbance and adults with a mental illness or co-occurring mental illness and substance abuse or other disorders, as an alternative to a general hospital or nursing facility.

#### **BARRIER ADDRESSED BY SOLUTION**

Under Medicaid Home and Community-Based Waivers, states can provide home and community-based care to individuals as an alternative to institutional placement, but the



state must demonstrate that the program will be cost effective. Since federal financial participation is not permitted under the Medicaid program for services to an individual who resides in an Institution for Mental Disease (IMD), CMS will issue technical assistance and guidance to improve state understanding of existing options under existing HCBS waivers.

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#### **SOLUTION I.A.4: ADMINISTRATIVE EFFICIENCIES**

CMS will act to increase the cost-effectiveness of home and community-based services by reducing certain administrative burdens, increasing reliance on electronic communications, and streamlining waivers, including:

- (a) **Promoting appropriate delegation and flexibility:** CMS will work with states to advance methods under Medicaid by which appropriate delegation of tasks and flexibility (e.g., nurse delegation) may reduce public costs or increase consumer control and satisfaction at no greater cost;
- (b) **Unnecessary level of care re-determinations:** Adjust regulation or propose other changes to permit states to waive the annual re-determinations of level of care for HCBS waiver eligibility for those categories of disability or illness determined by CMS to be statistically documented as stable; and
- (c) **Integrating target group services:** Permit states to target a single waiver to more than one major target group (e.g., aged and developmentally disabled) or, alternatively, to use functional criteria to define the eligible population to be served, provided there is a single service package and the total cost-effectiveness calculation is derived from the sum of discrete calculations in which costs are identified separately for each relevant institutional category (e.g., NF, ICF-MR, or hospital).

#### **BARRIER ADDRESSED BY SOLUTIONS**

These solutions promote cost-effective administration of HCBS waivers and related services by increasing efficiency.

- (a) **Promoting appropriate delegation:** Delegation of tasks by nurses to trained home health aides or family members, physician delegation to advanced practice nurses, and similar appropriate delegation of tasks may reduce public costs, or increase consumer control and satisfaction at no greater cost. CMS will work with states to advance methods by which such appropriate delegation may best be accomplished.
- (b) **Unnecessary level of care redeterminations:** States are currently required to reassess level of care for HCBS waiver eligibility on an annual basis. But many conditions do not change (e.g., an I.Q.). Requiring states to reassess such conditions each year simply adds wasteful administrative costs.

(c) **Integrating target group waivers:** Current CMS regulations require states to submit, administer, and report separately for waivers that serve different target groups. In particular, waivers serving elderly, people with a developmental disability, or people with a mental illness must all be administered separately. This adds unnecessary administrative expense. In addition, the decision to administer one or separate waivers for different target groups should be a state, rather than federal, decision.

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## **SOLUTION I.A.5: NATIONAL TECHNICAL ASSISTANCE STRATEGY**

CMS will ensure the provision of a coherent national program of technical assistance to all states to promote the most effective use of existing Medicaid authority in pursuit of enhanced opportunities for community living and community participation, including productive employment. This will include:

- Promoting the most effective use of existing Medicaid authority in pursuit of enhanced opportunities for community living and community participation;
- Developing a "Promising Practices" web site for community services;
- Ensuring effective administration of the System Change for Community Living grants in 2001 to assure optimum results, seeking assistance for states that did not receive grant awards in 2001; and
- Seeking methods by which additional assistance may be provided to states and local organizations dedicated to improving community-based services.

### **BARRIER ADDRESSED BY SOLUTION**

This initiative will be designed to fulfill HHS' obligation under the President's Executive Order to provide technical guidance and assistance. CMS also recognizes the need to increase technical assistance to states to help them negotiate complex Medicaid rules and procedures.

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## **SOLUTION I.A.6: HCBS STATE PLAN OPTION**

CMS will work with states and other stakeholders to consider statutory changes to establish a state plan option for comprehensive HCBS services.

### **BARRIER ADDRESSED BY SOLUTION**

Home and community-based services remain a "waiver" service under Medicaid, while institutional services are part of the standard state plan. This action would examine the potential to level the playing field by allowing states to adopt a comprehensive HCBS option as part of the state plan. Implementation options will also be explored. For example states might have up to 5 years as a "ramp-up period" to achieve statewideness and meet other requirements for state plan services.

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## **SOLUTION I.A.7: REMOVING ELIGIBILITY UNCERTAINTY AND DELAYS TO TRANSITION QUALIFIED PERSONS FROM INSTITUTIONS**

CMS will examine the costs and benefits of statutory change to establish a state option enabling presumptive Medicaid eligibility for people determined to need nursing facility or ICF-MR level of care who are being discharged from hospitals or other institutions to the community, similar to the presumptive eligibility for pregnant women but retaining the asset test. Hospitals now represent the single most frequent source of nursing facility admissions. This option would be designed to make it more feasible to discharge a hospitalized person to the community rather than to a nursing facility or similar institution, or to ensure that the institutional placement is one of short duration.

### **BARRIER ADDRESSED BY SOLUTION**

Aged or disabled individuals who require long-term care after their hospital stay are often faced with two main choices: either nursing home care or community services via a home and community-based services (HCBS) waiver. Nursing homes offer natural advantages to hospital discharge planning staff – they can offer on short notice a pre-packaged array of services, including room and board, and nursing home staff are skilled at expediting Medicaid applications. The relative speed with which a Medicaid application can be filed when a nursing home is involved often translates into a "default" decision to place the individual in a nursing home rather than returning home or attempting a community arrangement through HCBS waiver services.

Waiting one to three months for a Medicaid eligibility decision introduces an element of uncertainty that makes community services appear risky to the individual or family. Such uncertainty leads to higher rates of institutional placement than necessary.

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## **SOLUTION I.A.8: SERVICES FOR CHILDREN IN RESIDENTIAL TREATMENT**

CMS will propose statutory improvements to create an evaluated, 10-year HCBS demonstration as an alternative to Medicaid-funded psychiatric residential treatment centers. The demonstration would be limited by the total national number of enrollees and would allow states to set up home and community-based alternatives for children who would typically be served in psychiatric residential treatment facilities. States would be required to:

1. Provide state match at the same rate as Medicaid, use HCBS waiver criteria for financial eligibility, provide a service package equivalent to those required in Medicaid HCBS waivers, and closely coordinate such demonstration services with services available under the state Medicaid plan;
2. Ensure an adequate array of state plan services responsive to the support requirements of children with emotional disturbance; and
3. Maintain fiscal effort for services to children with emotional disturbances.

## **BARRIER ADDRESSED BY SOLUTIONS**

Medicaid provides inpatient psychiatric hospital services for children under age 21. The statute also extends these Medicaid benefits to children in psychiatric residential treatment facilities. CMS does not, however, consider residential treatment facilities to meet the definition of hospitals, therefore, they have not qualified as institutions against which states may measure HCBS waiver costs. It is believed that extending HCBS waivers as an alternative to residential treatment facilities would allow children to receive treatment in their own homes, surrounded by their families, at a cost per child which would be less than the cost of institutional care. The proposed demonstration, while limiting federal financial exposure by capping the total demonstration participation, will allow CMS to develop reliable cost and utilization data that would explain what we might expect if the HCBS waiver were permitted as an alternative to psychiatric residential treatment centers.

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### **B. Medicare: Eliminate or Reduce Institutional Bias**

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#### **SOLUTION I.B.1: DISCHARGE PLANNING**

CMS will review current Medicare and Medicaid discharge planning policies to ensure that institutions participating in Medicare and Medicaid provide more effective discharge planning for adequate and appropriate community-based care.

#### **BARRIER ADDRESSED BY SOLUTION**

One reason for the inappropriate institutionalization of people with disabilities is ineffective discharge planning. CMS will review and strengthen its discharge planning policies in order to ensure that individuals with disabilities receive appropriate placement and community-based services.

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#### **SOLUTION I.B.2: DURABLE MEDICAL EQUIPMENT IN MEDICARE**

CMS will examine methods to improve access to durable medical equipment (DME), including revisiting the operative definition of DME in light of the Ticket to Work statute to determine if it should include additional technologies to promote independence and community living. Other improvements may include:

- a. Allow durable medical equipment, prosthetics, orthotics and supplies (DMEPOS) to be furnished in a skilled nursing facility (SNF) for one month prior to discharge in order to allow the beneficiary to become acclimated to the equipment, make any necessary equipment modifications, and to allow for necessary teaching or training.
- b. Requiring a trial rental period for expensive medical equipment but generally purchased.

## **BARRIER ADDRESSED BY THIS SOLUTION**

Under current program rules in both the Medicaid and Medicare programs, access to durable medical equipment (DME) and other assistive devices that promote independence and productivity is generally viewed as restrictive.

Item “a” would address the fact that transition to the community on the part of residents of nursing facilities can be overwhelming, particularly if this transition involves adjustment to a new or upgraded prosthetic or orthotic device. Current CMS policy allows for pre-discharge delivery of DME, prosthetic or orthotic devices, if specific conditions are met, two days before discharge. This is insufficient time to allow for equipment modifications and teaching. Item “b” increases cost-effectiveness of Medicare purchases by permitting a rental period before a purchase is made. Currently, Medicare pays for purchase of expensive DME even when the equipment furnished may prove to be medically inappropriate for a particular patient, or the individual determines that the equipment may be less useful than anticipated. Such was the case with transcutaneous electrical nerve stimulation (TENS) prior to 1989. In 1989, the law changed to allow for a trial rental period before Medicare would pay for TENS. This provision achieved a reduction in unnecessary expenditures and beneficiary co-payments.

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## **C. Improving the Workforce Availability and Capability**

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### **SOLUTION I.C.1: DIRECT SERVICE WORKER NATIONAL DEMONSTRATION**

HHS will initiate, together with a limited number of volunteer states, a national demonstration designed to address workforce shortages of community service direct care workers. The demonstration will test the extent to which workforce shortages and instabilities might be addressed through (a) better coordination with the Temporary Assistance for Needy Families (TANF) program and (b) the availability of vouchers for worker health insurance or for tuition or day care credits. Participating states would be expected to develop options for workers to purchase affordable group health coverage through the state health insurance system or similar organized insurance group.

### **BARRIERS ADDRESSED BY THIS SOLUTION**

The absence of health insurance coverage for direct care workers in the community is one of the factors that limits the recruitment of workers, limits the ability of community programs to offer viable methods by which TANF recipients may reduce dependency of public programs, and limits the ability of people with disabilities to live in the community.

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## **SOLUTION I.C.2: COLLABORATION FOR DIRECT SERVICE WORKERS**

CMS and ASPE will collaborate on a joint initiative to (a) mobilize and make available to states a coherent body of information about methods to address worker shortage issues, (b) research significant issues, and (c) partner with foundations, other private sector organizations, the Department of Labor, and other agencies to formulate a comprehensive approach to the worker shortage issue.

### **BARRIER ADDRESSED BY THIS SOLUTION**

The difficulty of recruiting and retaining direct service workers is a strong theme in public input about barriers to community living. Various states and many local organizations have developed innovative approaches to this problem, but the information is not readily accessible. This initiative will mobilize such information, make it accessible, and enlist private sector partners in fashioning a long-term partnership strategy.

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## **D. Productive Employment**

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### **SOLUTION I.D.1: MEDICAID BUY-IN IMPROVEMENTS**

HHS will seek improvements to federal legislation that would permit states to:

- Establish a minimum threshold for work, up to 40 hours per month, in order for individuals to be eligible for participation in the state Medicaid buy-in programs, provided there are appropriate worker safeguards for building up to the minimum level of work effort during an individual's first six months of eligibility, and retaining eligibility for up to six months if employment is interrupted due to hospitalization, major illness, lay-off, or other misfortune;
- Remove the age limitation clause in the Ticket to Work legislation that eliminates Medicaid buy-in options when a worker with a disability is age 65 or older; and
- Use disability determination criteria in the Medicaid buy-in program that exclude employment status; In addition, CMS will seek changes to authorize the use of existing funds to provide technical assistance through direct contracts or grants with knowledgeable organizations skilled in working with states; adopt clarifications or proposals to enable states to reconcile conflicts between 1997 BBA provisions and 1999 Ticket to Work legislation; and seek an effective collaboration with SSA, DOE, DOL, HUD, SBA and others to coordinate federal initiatives and promote comprehensive solutions to the removal of employment barriers.

### **BARRIER ADDRESSED BY SOLUTION**

The suggested legislative improvements described above would permit states to require a minimum level of work effort in order for a worker with a disability to purchase

Medicaid health insurance under the Ticket to Work legislation. This reduces the potential for individuals to “game” the system, since there is not ability under current law for states to make such a requirement. Other potential improvements include removing the age discrimination currently in force in the Ticket to Work legislation that limits the “buy-in” option to those under age 65 and creates unnecessary unemployment when a covered worker attains the age of 65. Another improvement detailed above would permit states to remedy a technical problem in the legislation that reduces the effectiveness of the employment incentive. Other improvements would further promote employment for people with disabilities living in home and community-based settings.

## **II. Promoting Independence, Responsibility, and Consumer-Driven Services**

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### **SOLUTION II.A.1: PERSON-CENTERED PLANNING**

CMS will update its regulations regarding Medicaid case management to emphasize person-centered approaches pioneered by states.

#### **BARRIERS ADDRESSED BY SOLUTION**

It has been more than a decade since CMS regulations were revised to reflect statutory changes enacted in the intervening time period and advances in person-centered planning. This action will incorporate both such advances.

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### **SOLUTION II.B.1: SELF-DIRECTED SERVICES WAIVER**

CMS will provide states a simplified model waiver on electronic media (for 1115 and other waivers) that offer both person-centered planning and self-directed service options. CMS will also develop technical assistance materials outlining existing options for states to develop flexible, cost-effective and consumer-driven methods of providing home health or personal assistance services.

#### **BARRIER ADDRESSED BY SOLUTION**

The need for additional and self-directed services emerged as a major theme from the National Listening Session and from other public input. This solution will help self-directed services to succeed by providing states and providers with the information and tools to offer self-directed care, thereby increasing the likelihood that self-directed care will be made available for individuals with disabilities and their families. By providing states with a simplified model waiver template, CMS will:

- Promote flexibility for states that are seeking to increase the opportunities afforded consumers in deciding what types of services to receive, and from whom to receive them;
- Provide states with more streamlined applications for waiver programs thus reducing the administrative burden for preparing proposal submission; and
- Facilitate states' initiatives for *Olmstead* compliance.

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## **SOLUTION II.C.1: HEALTH AND DISABILITY EDUCATION AND MENTORING**

The Centers for Disease Control and Prevention, in collaboration with the Department of Education and others, will continue its educational and self-help curriculum, pioneered with the nation's Independent Living Centers, entitled "Living Well with a Disability." The initiative enables individuals with disabilities to benefit from increased knowledge regarding ways to take charge of one's health and daily living challenges.

### **BARRIERS TO BE ADDRESSED**

Insufficient knowledge or expertise about methods of taking charge of one's health and well-being leads to higher reliance on professionals and higher incidence or exacerbation of illness and disability. "Living Well With a Disability" is an 8-week curriculum that has been developed to address these barriers. The program has been pre-tested in community settings in nine Independent Living Centers throughout the country. Initial data from cost-effectiveness research conducted by the University of Montana and the University of Kansas indicate a net benefit to Medicare, Medicaid, and private insurance carriers. The CDC's Office on Disability and Health will be responsible for the program and will collaborate with CMS, the Department of Education, and others to ensure the most effective application of these methods that will augment the ability of people with a disability to affect their health outcomes.

## **III. Assistance to Families and Informal Caregivers**

### **SOLUTION III.A: MODEL WAIVER AND DEMONSTRATION FOR FAMILY AND CAREGIVER SUPPORT**

CMS will develop a model simplified, streamlined, electronic waiver application form (including 1915(c) and 1115 waiver options) designed to permit states to offer a flexible array of supports for caregivers and the individuals for whom they provide assistance.

In connection with this waiver, ADD, AoA and SAMHSA will explore coordinating grant funds, and CMS will coordinate Medicaid state plan service options and Medicaid



waivers within the structure of a coherent demonstration. The initiative will be designed to:

1. Keep families intact, thereby reducing the demand for out-of-home placement;
2. Provide families flexibility in determining and selecting what services and supports the family needs to retain the individual in the family's or the individual's own residence (recognizing the distinctions between what they want and need) in exchange for the agreement to work within an individually determined budget; and
3. Provide states with a template to serve as a guide to expand family support options.

### **BARRIER ADDRESSED BY SOLUTION**

Families, friends, and community support networks provide the great majority of long-term care in the United States. To the extent such family and community caring can be promoted and supported, public costs can be reduced.

In addition, a family support model waiver program would strengthen supports to families and, possibly, permit the person to live with the family longer. States and families that have the ability to choose items in the state's waiver program and flexibility to "customize" services generally find higher levels of consumer and family satisfaction.

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### **SOLUTION III.B.1: MEDICAID RESPITE SERVICE FOR ADULTS**

HHS will seek authorization and funding from Congress to conduct a ten year national demonstration that would allow states to provide respite care (temporary care that offers support to family caregivers) for adults as a fixed budget demonstration. The state option would provide essential relief to unpaid caregivers (including, for example, persons providing continuous care and supervision to an individual with Alzheimer's or mental illness) within specified federal limits. States could establish more restrictive limits, utilization controls. States would be required to provide state match at a ratio equivalent to the ratio in Medicaid. States would be required to maintain fiscal effort for caregiver support.

### **BARRIER ADDRESSED BY SOLUTION**

Respite care – temporary care that offers support to family caregivers – is the service most often requested by families in an effort to keep their family member with a disability at home. Caring for a family member with a disability is highly stressful. Unrelieved caregiver burden is a major contributing factor to caregiver illness, marital discord and divorce, and institutionalization of individuals with a disability. Many family members report that they are unable to leave their family member with a disability with another relative or sitter, that some day care centers will not accept people with disabilities, and that it is not safe for the individual with the disability to be left at home alone. Occasional periods of respite care can significantly reduce stress in the family and enhance the ability to keep the family member at home and in the community.

Respite care can take many forms. Care may be provided in the family home,

allowing the care-taking family member to get away for a few hours, or in the respite provider's home. It can also be provided in day programs and senior centers. In some cases, group homes or other facilities may provide overnight or weekend care.

Medicaid requirements currently limit respite care to home and community-based waiver programs. Such programs are limited to people who already require institutional level of care, often have long wait lists, and are best suited for individuals who require a full package of services rather than a targeted service such as respite. To the extent a Medicaid respite service extends the capacity of families to keep their loved ones at home and delay or prevent the use of more expensive forms of care, the service could result in some offsetting cost savings for Medicaid and Medicare

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### **SOLUTION III.B.2: DEMONSTRATION: RESPITE SERVICE FOR CAREGIVERS OF CHILDREN WHO HAVE A SUBSTANTIAL DISABILITY**

CMS will seek authorization and funding from Congress to implement an evaluated, 10-year demonstration to provide essential relief to caregivers of children who have a substantial disability. The demonstration would be limited by the total national number of enrollees and would allow states to establish flexible respite services for such caregivers, tailored to the needs of individual families. The demonstration would also include an evaluation of the possible effects of including supervision under personal assistance services. In this flexible "Medicaid-like" demonstration states would be required to:

- (a) Provide state match at the same rate as Medicaid, use HCBS waiver criteria for financial eligibility, provide a service package equivalent to those required in Medicaid HCBS waivers, and closely coordinate such demonstration services with services available under the state Medicaid plan;
- (b) Ensure an adequate array of state plan services responsive to the support requirements of children with emotional disturbance; and
- (c) Maintain fiscal effort for services to children with emotional disturbances.

### **BARRIER ADDRESSED BY SOLUTION**

Caregivers of children with a disability face the same barriers and challenges as those faced by caregivers of adults, described previously. However, special issues pertain to the question of developing a national program under Medicaid for support of caregivers of children. One concern is that under Medicaid's Early, Periodic Screening Detection and Treatment Program (EPSDT) an optional Medicaid service, by law, is mandatory upon states with regard to children determined to require such services. It is not the intention of this HHS initiative to create mandates for states that might require substantial state matching funds. A demonstration program will permit CMS and states to obtain more specific cost and utilization data, evaluate the effects of improved caregiver support on the well-being of families and on possible savings in other programs (such as reduced out-of-home placements).

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## **SOLUTION III.C: ACTION PLAN FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES**

HRSA's Maternal and Child Health Bureau will take the lead in developing and implementing a plan to achieve appropriate community-based services systems for children and youth with special health care needs and their families. Components of the plan may include:

1. Development of community-based systems of services that are inclusive of children with special health care needs (CSHCN) and their families, where substantial decision-making authority is devolved from the federal government to the states to the communities.
2. Recognition that families are the ultimate decision-makers for their children and encouragement of participation in making informed decisions.
3. Development of standardized elements of the medical home for CSHCNs. In addition, the agency will develop and disseminate models of the medical home, and provide additional training resources to primary care professionals to develop medical homes.
4. Review of the variety of reimbursement mechanisms that impact children with special health care needs.
5. Through the Maternal and Child Health Block grant (Title V of the Social Security Act), and the Newborn Genetics Program (Title XXVI of the Child Health Act), expansion and strengthening of newborn screening systems and promote ongoing screening of CSHCN (incorporating EPSDT into the medical home concept).
6. Ensuring that youth with special health care needs receive the services necessary to transition to all aspects of adulthood, including from pediatric to adult health care, from school to employment and to independence.

### **BARRIER ADDRESSED BY SOLUTION**

For children with special health care needs, specific barriers include access to: (1) comprehensive, family-centered care; (2) affordable insurance; (3) early and continuous screening for special health care needs, and (4) transition services to adulthood. With respect to families of such children, issues relate to family satisfaction and the complexity and organization of services resulting from fragmentation and multiple funding streams. Developing a plan to address these barriers is a necessary first step to improving access to community-based services for children with special health care needs.

## **IV. Coordination and Reduction of Fragmentation**

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### **A. Coordination Within HHS**

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#### **SOLUTION IV.A.1: ESTABLISH AN HHS OFFICE ON DISABILITY AND COMMUNITY INTEGRATION**

HHS will establish an Office on Disability and Community Integration. The Office on Disability and Community Integration will oversee the coordinated development and implementation of policies, programs and special initiatives within HHS that impact people with disabilities regardless of age or type of disability. The Office on Disability and Community Integration will serve as the focal point within the Department for disability issues including the coordination of disability science, policy, programs and special initiatives within the Department and with other federal agencies. The Office will also carry out functions related to interagency coordination, including: ensuring that HHS is an effective participant in the Interagency Council on Community Living (described below at IV.B.1); and mobilizing and supporting HHS components in devising and carrying out specific interagency efforts.

#### **BARRIER ADDRESSED BY SOLUTION**

Both the HHS self-evaluation and public input processes identified fragmentation and lack of coordination within HHS as a significant barrier to community living for individuals with disabilities. The public input process and HHS self-evaluation made clear the need to oversee the coordinated development and implementation of policies, programs and special initiatives within the Department that impact people with disabilities regardless of age or type of disability. The Office on Disability and Community Integration would fulfill this function. The creation of such an entity is strongly supported by HHS components and stakeholders.

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#### **SOLUTION IV.A.2: HHS DISABILITY ADVISORY COMMITTEE**

HHS will establish a Disability Advisory Committee that includes representation by all of the constituencies described in Executive Order 13217, including individuals with disabilities, family members of individuals with disabilities, advocacy organizations, providers and state and local government representatives. The Disability Advisory Committee will review and advise HHS on the implementation of solutions set out in this report, and will provide information and advice to the HHS Office on Disability and

Community Integration on community integration issues. The Disability Advisory Committee will be established consistent with the requirements of the Federal Advisory Commission Act (FACA) and will include representation from the National Council on Disability.

#### **BARRIER ADDRESSED BY SOLUTION:**

Through the public input process mandated by the Executive Order, people with disabilities, family members, providers, state and local government entities and national organizations came forward to provide federal agencies with valuable insights and information about barriers to community-based services and solutions to these problems. The federal government's interaction with these stakeholders underscored the importance of listening to the people who are closest to problems and using their real-life expertise to guide us toward effective solutions. These individuals and organizations also expressed an interest in future opportunities to be involved in the development and implementation of government efforts to improve the availability of community-based service. The continued involvement of these stakeholders after the submission to the President of this report will be critical to the success of government efforts to facilitate community integration and is consistent with the expressed interests of the Administration and the leadership of HHS.

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## **B. Coordination Among Federal Agencies**

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### **SOLUTION IV.B.1: FORMALIZE PERMANENT INTERAGENCY COUNCIL ON COMMUNITY LIVING**

HHS proposes that the President formalize permanently the Interagency Council on Community Living (ICCL), convened by HHS Secretary Thompson in July 2001 to accomplish the tasks set out in Executive Order 13217. The ICCL would be comprised of all agencies involved in implementation of the Executive Order, with the addition of other agencies as appropriate, including the Internal Revenue Service and the Equal Employment Opportunity Commission (EEOC). Designated members would be Secretaries, agency heads, or their functional equivalents. In addition, staff would be assigned to conduct the ongoing interagency work. HHS proposes that the Council articulate a strategic interagency plan to expand and promote home and community-based services, and to address, at a minimum, issues related to: housing; workers with disabilities; transportation; the long-term care workforce; assistive technology; and education.

The Council will formulate short and longer range action steps. All efforts will be made to develop a small number of interagency demonstration programs, through consolidation of current programs. The Council will ensure that the specific population needs of Tribal communities and children are addressed, and that cultural, ethnic, and life span issues are addressed.

## **BARRIERS ADDRESSED BY SOLUTION**

Government programs that serve individuals with disabilities, including those programs that are designed to or can facilitate community integration, are administered by several different federal agencies. These programs sometimes fail to meet the needs of individuals with disabilities as effectively as possible due to inadequate programmatic coordination and communication across agencies. Throughout the public comment process, individuals and organizations frequently identified fragmentation and lack of communication as a primary barrier to community integration for individuals with disabilities. Agencies identified this barrier as well. The President’s Executive Order provided federal agencies with the impetus to work together to identify barriers to community living and to evaluate agency programs, policies, statutes and regulations. It is apparent from this process that continued interagency coordination is essential to fulfill the goals of the Executive Order and to effectively implement the solutions identified by federal agencies.

## **V. Accountability and Fulfillment of Legal Obligations**

### **A. Complaint Resolution and Voluntary Compliance**

#### **SOLUTION V.A.1: ALTERNATIVE DISPUTE RESOLUTION**

OCR and the Department of Justice (DOJ) will develop a pilot program to use DOJ's alternative dispute resolution (ADR) program for the resolution of appropriate complaints filed with OCR alleging that individuals with disabilities are not being provided services in the “most integrated setting appropriate to their needs,” under ADA Title II regulations as interpreted in the *Olmstead* decision.

#### **BARRIER ADDRESSED BY SOLUTION**

Executive Order 13217 requires HHS, along with the Department of Justice, to “fully enforce” Title II of the ADA, and specifically directs that alternative dispute resolution process be used whenever possible to resolve complaints alleging unjustified institutionalization. This solution provides for OCR-DOJ collaboration in developing an ADR pilot program.

OCR has been working with states to facilitate planning for the community integration of individuals with disabilities, in some cases reviewing state *Olmstead* plans to determine whether plans are sufficient to resolve the issues raised in “most integrated setting” complaints filed against states. OCR has successfully resolved directly with the state or local jurisdictions a number of these individual complaints. However, there are some

situations where a neutral third party may facilitate resolution. These complaints may be especially amenable to resolution via ADR.

Since 1994, DOJ has maintained an ADR program in which professional mediators who have been trained about ADA legal requirements help adverse parties devise mutually acceptable solutions in appropriate cases involving alleged violation of the ADA. Using this established ADR program, OCR and DOJ will develop a pilot designed to offer ADR on a trial basis to a limited number of complainants.

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## **SOLUTION V.A.2: REGULATORY REVISIONS TO FACILITATE ACCESS TO RECORDS**

HHS will recommend that ADA Title II enforcement regulations be amended to clarify that the standards for obtaining access to records during investigation under ADA Title II are consistent with those under Section 504.

### **BARRIER ADDRESSED BY SOLUTION**

Under regulations setting out OCR's enforcement authority under Section 504 of the Rehabilitation Act of 1973 (prohibiting disability-based discrimination by recipients of federal funding), OCR has access to documents that may be pertinent to determine compliance. The statutory language of Title II of the ADA establishes that the "remedies, procedures and rights" of Section 504 apply in allegations of discrimination under Title II. But, the regulations regarding Title II of the ADA do not contain the same specific document access provisions as the Section 504 regulations. Amending the Title II regulations would ensure that these regulations are consistent with Title II's statutory language, and clarify that OCR has access to needed documents when conducting an investigation concerning compliance with the most integrated setting requirement where the target of the investigation is a state or local government entity that does not receive HHS funding. This solution will be evaluated and implemented in consultation with DOJ.

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## **B. Specialized Technical Assistance and Related Activities**

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### **SOLUTION V.B.1: BROAD DISSEMINATION OF INFORMATION ABOUT VOLUNTARY COMPLIANCE**

HHS will expand its dissemination to states, Tribes, and other stakeholders of information about: voluntary compliance with the ADA's most integrated setting regulation and the *Olmstead* decision; promising practices in the provision of services in the most integrated setting to individuals with disabilities; specific examples of individuals with disabilities who have moved from institutional to community life; and other relevant developments.

## **BARRIER ADDRESSED BY SOLUTION**

States and other public entities that want to comply with the law can benefit from access to information about promising practices. HHS components have access to some of this information, but need to do a better job in ensuring widespread dissemination. In addition, although some information may not currently be available to HHS components, this information could be gathered and made available through expanded technical assistance and enforcement efforts. The widespread dissemination of information about the means by which states have come into voluntary compliance with the ADA's most integrated setting requirement will increase the knowledge base of states, Tribes and other stakeholders nationwide, and can serve to spur the community integration of additional individuals with disabilities.

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### **SOLUTION V.B.2: CLARIFICATION OF MEDICAID POLICIES AFFECTING INDIVIDUALS WITH PSYCHIATRIC AND CO-OCCURRING DISORDERS**

CMS will clarify existing Medicaid policies identified as confusing or prone to misunderstanding that relate to community-based services for persons with psychiatric and substance abuse disabilities and children with serious emotional disturbances, and will provide necessary technical assistance on these policies to states to assist them to make full use of existing Medicaid programs. Technical assistance, with assistance from SAMHSA, will be provided to states in the following areas:

- The range of mental health-related services for which the rehabilitative option can be used, including specific examples from individual states, and the development of templates;
- The availability and limits of administrative services to ensure fulfillment of the statutory provisions for continued eligibility and discharge preparation for residents recognizing federal financial participation is not available for state plan services to the individual while an IMD resident;
- The eligibility guidelines for adults with psychiatric and substance abuse disabilities in nursing homes and psychiatric units of general hospitals for home and community-based waiver services; and
- The availability and application of demonstration grants under the Work Incentives Improvement Act of 1999 for employed persons with psychiatric and substance abuse disabilities.

## **BARRIER ADDRESSED BY SOLUTION**

Inconsistencies across the states exist in the use of Medicaid programs for persons with psychiatric and substance abuse disabilities and children with serious emotional disturbances. Developing and providing technical assistance to the states will enhance states' ability to more consistently ensure access to community-based services and enhance community living for these persons.



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**SOLUTION V.B.3: INCREASED REGIONAL EFFORTS TO PROVIDE TECHNICAL ASSISTANCE TO STATES TO PROMOTE *OLMSTEAD* COMPLIANCE**

HHS will create intradepartmental workgroups in each HHS region to work with states to promote compliance with the ADA and the *Olmstead* decision. These groups will bring together key federal components, including CMS, OCR, AoA, SAMHSA, HRSA, ACF, IHS and others to provide hands-on technical assistance across programs on how to provide expanded, better, more effective and appropriate community services for individuals with disabilities. The regional teams will work with states, particularly those developing the comprehensive, effectively working plans suggested by the *Olmstead* decision, to identify potential sources of funding and to implement best practices. In addition, these regional teams (or subgroups of these teams) will work with states on other cross-cutting areas related to community integration.

**BARRIER ADDRESSED BY SOLUTION**

Creating work groups that span across programs will enhance the ability of the federal government to provide states and Tribes with effective technical assistance on community services. Through increased communication and coordination among HHS components, these work groups will enhance states' ability to achieve *Olmstead* compliance.

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**SOLUTION V.B.4: TECHNICAL ASSISTANCE ON SERVICES FOR OLDER PERSONS**

The Administration on Aging (AoA) will provide more technical assistance and guidance to states regarding the options available to them to creatively shape their services to best meet the needs of their elderly populations.

**BARRIER ADDRESSED BY SOLUTION**

The 2000 Amendments to the Older Americans Act allowed states to develop demonstrations, in limited areas of the state, to test innovative approaches to assist older individuals. Many state units on aging are unsure of how to use this new flexibility to demonstrate and implement new program design and coordination. Technical assistance activities by AoA will help advise state units on aging on ways in which using the waiver provision can facilitate the community integration of individuals with disabilities.

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## **C. Effective Quality Assurance and Quality Improvement**

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### **SOLUTION V.C.1: DEVELOP A MULTI-PRONGED STRATEGY TO ADDRESS QUALITY OF CARE ISSUES IN HOME AND COMMUNITY-BASED SERVICES**

HHS will address quality of care issues in home and community-based services through a multi-pronged strategy developed in consultation with states and individuals with disabilities or long-term illnesses. This strategy will include:

- Establishing defined expectations for waiver and non-waiver home and community-based services, including that states establish their own quality improvement strategies for HCBS services;
- Assisting states in using the results of CMS quality reviews;
- Assisting states to design better systems of quality assurance and improvement that increase the state's response capability and prevent future problems;
- Providing technical assistance to states and CMS regions in effective systems design or quality improvement strategies;
- Analyzing and testing new approaches to ensuring and improving quality;
- Implementing new quality assurance and improvement systems uniquely suited for services in one's own home; and
- Ensuring that the specific population needs of Tribal communities and children are addressed and ensuring that cultural, ethnic and lifespan issues are addressed.

#### **BARRIER ADDRESSED BY SOLUTION**

Under current regulations, states must provide CMS with prospective assurances of quality in their waiver applications. Specifically, states must assure CMS that safeguards are in place to protect the health and welfare of HCBS waiver enrollees; that there is financial accountability for funds expended; that evaluation of enrollee need is valid and that enrollees are informed of and have a choice regarding whether they will receive care in a nursing facility or in the community.

However, expectations about specific state responsibilities are unclear and CMS does not have adequate tools to ensure fulfillment of these assurances or work effectively with states to make needed improvements. This initiative will provide resources to enable CMS to work collaboratively with states, national associations, and people who have a disability or long-term illness to clarify or develop important expectations about necessary elements in an effective QA/QI system. Events in multiple states over the past several years underscore the need to be vigilant about quality. A multi-pronged strategy is needed to ensure adequate standards and safeguards and to ensure that adequate actions are taken when problems are identified.

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## **SOLUTION V.C.2: QUALITY IMPROVEMENT**

Through an independent national contractor, CMS will (a) assess the current state of the art in community-based quality systems and (b) assist states in the following: using the results of CMS quality reviews; taking prompt remedial action for identified problems in HCBS programs; designing better systems of quality assurance and quality improvement that increase the state's response capability and prevent future problems; ensuring effective system design or quality improvement strategies; establishing quality standards and performance measures for all waiver and non-waiver home and community-based services; analyzing/testing new approaches to assuring and improving quality, and implementing new quality assurance and improvement systems uniquely suited for services in one's own home.

### **BARRIER ADDRESSED BY SOLUTION**

The ultimate test of any quality system is whether the results are effectively used to (a) remedy specific identified problems and (b) improve the overall system to prevent future problems. These results are not sufficiently prevalent in the current system. This initiative will enable CMS to assess more closely existing systems and ensure the provision of direct assistance to state partners.

A national contractor will work with CMS, states, disability rights specialists, and other stakeholders to incorporate new and more effective quality assurance techniques in fulfillment of CMS responsibilities, including use of quality improvement practices pioneered in the private sector. The contractor will provide effective back-up to regional offices, provide the mobile capacity to move resources quickly where problems are most intense, be able to conduct more intensive reviews after the regional offices have identified initial problems, and work with CMS and the states to fashion more effective remedial strategies. Most importantly, the contractor will work with states and CMS to reduce the need to rely on after-the-fact inspection in favor of more preventative quality improvement approaches now widely used in the private sector.

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## **SOLUTION V.C.3: ACTION REINVESTMENT FOR QUALITY**

In consultation with states and people with a disability or long-term illness, CMS will develop improvements to HCBS waiver administration for legislative or regulatory consideration that will increase the prospect for prompt and effective remedy of identified problems. The improvements will reduce the need to rely on existing authority to terminate (or "non-renew") entire waivers if a state has failed to fulfill the statutory requirement for a system that will reasonably assure the health and welfare of HCBS waiver participants.

## **BARRIER ADDRESSED BY SOLUTION**

CMS has responsibility for assuring that states operate Home and Community-Based Services (HCBS) waivers and managed care waivers in the best interests of the individual and in a manner that assures the health and welfare of the beneficiary. The Social Security Act requires that a state provide assurances to CMS that it will ensure the health and welfare of waiver participants. However, CMS is unable to ensure corrective action if a state fails to make adequate improvements following the identification of serious quality issues as the result of a CMS review.

If a state fails to fulfill its assurances regarding quality, the principal enforcement tools available to CMS are to refuse renewal or to terminate a waiver. These actions are generally stronger than required. They also impact negatively on large numbers of people who rely on the waivers for their ability to live in their own homes or in the community and whose quality of service may be excellent. For such HCBS waiver participants, CMS termination of an entire waiver may mean (a) the termination of services (because comparable services are generally not available in Medicaid State plans); (b) forced relocation to a different living arrangement (and sometimes, transfer trauma); and (c) for some people, the loss of Medicaid eligibility.

The proposal offers CMS the ability to take reasonable action that is proportionate to the size of the problem. It will ensure that enforcement does not deny services to individuals served under HCBS waiver programs.

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## **D. Specialized Technical Assistance and Related Activities**

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### **SOLUTION V.D.1: APPLIED KNOWLEDGE**

CMS will work with states, universities, foundations and others to ensure that there is an adequate base of applied research and knowledge to inform public policy-making with regard to (a) the impact of the Medicaid and Medicare actions under the President's Executive Order (b) state initiatives to improve community living services, (c) methods for designing long-term care systems so that they promote the ADA and are capable of addressing expected population growth due to demographic changes, and (d) methods for designing quality assurance and improvement systems uniquely suited for services in one's own home.

## **BARRIER ADDRESSED BY SOLUTION**

The HHS self-evaluation process identified some areas in which data concerning the community integration of individuals with disabilities is nonexistent or insufficient. Moreover, there will be a need to examine the effectiveness of HHS' actions to implement Executive Order 13217 and the New Freedom Initiative. This solution will help focus and organize the

gathering and analysis of needed data, and will, in turn, support future public policy-making related to community integration.

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## **SOLUTION V.D.2: ADEQUATE MANAGEMENT INFRASTRUCTURE**

CMS will develop an initiative to improve the ability and infrastructure at state and federal levels to account for HCBS and institutional expenditures, analyze trends, identify potential for improvement, implement quality improvement processes, and promote community living through improved management capability and research.

### **BARRIER ADDRESSED BY SOLUTION**

States often lack the infrastructure and specialized expertise to evaluate spending and trends with respect to institutional and community care, engage in long-term planning and systemic reform with respect to community-based care, and manage an expanding community service system effectively.

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## **E. Other Actions that Promote Accountability and Capability**

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### **SOLUTION V.E.1: SYSTEMS CHANGE GRANTS**

CMS will offer “phase II” of its "Systems Change Grant Program" to assist states in developing services and infrastructure necessary to enable people of any age or disability to live and participate in their communities.

### **BARRIERS ADDRESSED BY SOLUTION**

Developing more responsive community systems requires a significant investment of planning, collaboration, and systems development. State and local organizations often lack the resources and access to expertise necessary to accomplish these results. More promising results can be achieved from the type of state-federal-private sector partnership that was initiated in calendar year 2001.

During the first phase of HHS’ Systems Change for Community Living grants, HHS awarded approximately \$64 million in new grants to 37 states and one territory to develop systemic changes to promote community integration. This includes \$40.8 million awarded to states designing and implementing effective and enduring improvements in community long-term support systems to enable children and adults with disabilities or long-term illnesses to live and participate in their communities. Another \$7.6 million was awarded to support states' efforts to improve personal assistance services that are consumer-directed or offer maximum individual control. Next, \$11.1 million in "Nursing Facility Transitions" grants was awarded to help states transition eligible individuals from nursing facilities to the community. Finally, \$4.9 million was awarded to states to provide technical assistance,

training and information to states, consumers, families and other agencies and organizations.

“Phase II” of the system change grants would help states take their efforts to achieve systemic reform to the next level. Applications for assistance during the first phase came from 51 states and territories, and totaled \$240 million in proposed improvements. However, CMS was only able to respond to about 30 percent of such plans. Establishing a second phase of the program will build on the planning already accomplished by states that responded to the program in calendar year 2001. It will also enable states that were not funded to continue their momentum and augment their efforts to improve their systems.

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## **SOLUTION V.E.2: DISABILITY POLICY FELLOWS PROGRAM**

HHS will establish a program to recruit the expertise of talented individuals who have direct personal experience with a major disability to work in HHS agencies for 1-2 year assignments on a full- or part-time basis, under the Intergovernmental Personnel Act (IPA). HHS will also establish a companion initiative to permit key HHS components that administer disability programs to hire, in permanent positions, a limited number of highly capable individuals with a disability. These personnel programs will be undertaken consistent with the federal government’s responsibilities under Section 501 of the Rehabilitation Act, Executive Order 13163 and the department’s Plan for Employment of People with Disabilities in the federal government.

## **BARRIER ADDRESSED BY SOLUTION**

As a result of the HHS self-evaluation process, some HHS components expressed the view that HHS’ work in community integration of individuals with disabilities could be enhanced by increasing the representation of individuals with disabilities in the HHS workforce. These components articulated an interest in reviewing employment practices in order to facilitate the employment of individuals with disabilities. The desirability of increasing the representation of individuals with disabilities in the federal workforce is also reflected by Section 501 of the Rehabilitation Act of 1973. The 1973 Rehabilitation Act requires each federal government agency to create and annually update an affirmative action program for the hiring, placement and advancement of individuals with disabilities. Executive Order 13163 later directed federal agencies to take affirmative steps to hire individuals with disabilities and expand employment outreach efforts, required federal agencies to prepare a plan to increase the opportunities for individuals with disabilities, and estimated that the federal government would be able to increase its hiring of individuals with disabilities over a five-year period. HHS’s Plan for Employment of People with Disabilities in the federal government includes such objectives as recruiting people with disabilities widely for job opportunities at all levels. The HHS Plan also includes such strategies as developing and implementing strategies to meet specific hiring goals and to continuously improve the quality of work life for individuals with disabilities. HHS will establish the Disability Policy Fellows Program by March 1, 2002.

# Appendix A

## Barriers to Community Living

### INTRODUCTION

Appendix A summarizes existing research and discusses the barriers identified by HHS components and the various stakeholders who provided input during the HHS self-evaluation process.

Review and analysis of all the input received during HHS' self-evaluation process, including stakeholder input, revealed barriers to community living for people with disabilities that fit into five major categories:

- System structure and financing;
- Responsiveness of services to individual needs;
- Supports for family and informal caregivers;
- Fragmentation and lack of coordination between programs and agencies; and
- Accountability and legal compliance.

### HHS COMPONENT SELF-ASSESSMENT

To begin the self-evaluation process, HHS Deputy Secretary Claude Allen convened a department-wide task force known as the "New Freedom Initiative Group." The Deputy Secretary asked each of HHS' seventeen components to appoint a senior level manager as well as a key staff person to the group. The Deputy Secretary then directed all HHS components to conduct separate self-evaluations. Each component was asked to look at its policies, programs, statutes and regulations and explore two basic questions:

1. Whether any policy, program, statute or regulation inhibited the ability of individuals with disabilities to live in the community; and
2. Whether any of these could be revised or modified to improve the availability of community-based services for people with disabilities.

Agencies were also asked to summarize current or planned activities or programs that promote the ability of individuals with disabilities to live in home and community-based settings.

To complete these tasks, the components reviewed and examined: policies and procedures pertaining to program administration; regulations that relate to the provision of community services; laws related to how community services and supports are structured; program guidance documents, data systems and research related to the provision of community services; budget and program planning documents; information

about past and current component activities; and administrative materials such as contract documents and human resource policies.

A reporting form, or template, was drafted by the "Report Task Force," a subgroup of the New Freedom Initiative Group, for each component's use in the self-assessment process. Completed templates were reviewed by the Report Task Force, which evaluated the submissions and asked components to supplement where necessary. The Report Task Force then drafted and distributed a matrix summarizing all component submissions. The primary barriers and solutions identified by components to address these barriers, as a result of both the self-evaluation and public input processes, are discussed in Chapter III.

Biweekly meetings of the New Freedom Initiative Group permitted discussion of Report progress, particularly around the creation of vehicles through which to obtain the public input required by the Order. The Preliminary Report of Federal Agencies, Actions to Eliminate Barriers and Promote Community Integration released on December 21, 2001, describes the public input process in detail, including the combined effort of 10 federal agencies spearheaded by HHS to gather input via three specially created avenues-- a day-long "National Listening Session;" a national toll free conference call; and a formal public comment period (via notice published in the *Federal Register*).

Finally, as part of the self-evaluation, HHS reviewed existing studies conducted both in the public and private sectors regarding barriers to community living for people with disabilities. Each component within HHS was asked to identify existing reports and research. Hundreds of studies were identified through this process. HHS staff narrowed the list by concentrating on recent studies (primarily within the past three years) and those considered significant because they represent a comprehensive, in-depth or unique review of the issues. As a result, HHS read, reviewed and summarized 54 studies, which helped to frame our analytic approach to the agency's self-evaluation.

Following the component self-assessment and the receipt of public input, the New Freedom Initiative Group formed subgroups around the critical subject areas that emerged. These "solutions subgroups" analyzed solutions offered in both the component assessment process and through the public input process and drafted recommendations. The solutions were vetted in multiple meetings of these groups and circulated and revised to achieve consensus. The Report Task Force relied on this process and other information to submit a draft report to Secretary Thompson for his review and approval.



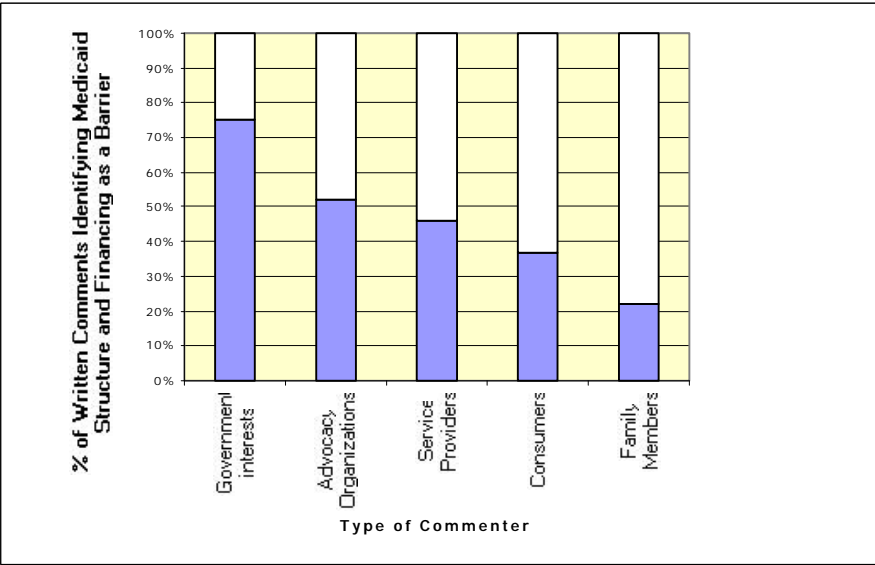
# Structure and Financing of Programs Administered or Funded By HHS

HHS components identified a number of barriers that related directly to the structure and financing of programs operated by HHS. A significant proportion of the comments from public respondents focused on these same barriers with a particular focus on two major programs: Medicaid and Medicare.

## A. Medicaid

Medicaid is a major source of funding for nursing homes and intermediate care facilities. Increasingly, it also pays for community-based care either through optional services or through home and community-based waiver programs. The barriers posed by Medicaid to community living for people with disabilities were a significant focus of public input. Indeed, a large percentage of written comments received during the public input process identified Medicaid’s structure and financing as chief among the barriers to achieving community living.

**TABLE: PERCENTAGE OF WRITTEN COMMENTS IDENTIFYING MEDICAID STRUCTURE AND FINANCING AS A MAJOR BARRIER TO COMMUNITY LIVING**



## 1. Institutional Bias

Institutional bias in Medicaid was identified as a major barrier by HHS components and all stakeholder groups including state and local governments. Research confirms that institutional bias is a significant obstacle to community living.<sup>10</sup> Institutional bias stems largely from the way in which the Medicaid program was structured nearly 40 years ago. Today, approximately 75 percent of Medicaid long-term care funding goes to pay for institutional care, while only 25 percent is directed toward home-and community-based services.

As studies have documented, institutional bias is embedded in statutory and regulatory provisions that define the Medicaid benefit package and eligibility rules.<sup>11</sup> Under the federal Medicaid program, states are required to provide nursing facility benefits to any individual aged 21 or over who meets financial eligibility criteria and requires a nursing facility level of care. Once an individual is eligible to receive nursing facility care, the Medicaid benefit is comprehensive.

In contrast, Medicaid-funded community-based care, such as personal care<sup>12</sup> and rehabilitation services,<sup>13</sup> are provided at a state's option. States that want to provide more comprehensive community-based care for individuals who meet a nursing facility level of care must obtain a waiver of federal Medicaid program rules. However, waiver services also are optional, and states have broad discretion to limit the number of people served in the waiver and to limit the array or amount of services or impose service caps that limit the quantity of services provided. In addition, many waiver programs have long waiting lists of

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<sup>10</sup> Charlene Harrington, et. al., *A review of Federal Statutes and Regulations for Personal Care and Home and Community Based Services: A Final Report*, University of California Department of Social & Behavioral Sciences (May 1998, revised July 1999) [hereafter "Harrington et al."].

<sup>11</sup> Williams, *Home and Community-Based Services Work Group Progress Report*, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services (1999) [hereafter Williams]; Pamela Dautel and Lex Frieden, *Consumer Choice and Control: Personal Attendant Services and Supports in America* (1999).

<sup>12</sup> Since the mid-1970's, states have had the option to include coverage for personal care services in their Medicaid programs. Personal care services may include assistance with Activities of Daily Living (ADLs) such as bathing, toileting and dressing, as well as Instrumental Activities of Daily Living (IADLs) such as personal hygiene, light housework, laundry, meal preparation, grocery shopping, money management, etc. For persons with cognitive impairments, personal care services may also include cueing, along with supervision, to ensure that individuals perform the tasks properly. In 2000, 27 states covered personal care services. U.S. Dept. of Health and Human Services, *Understanding Medicaid Home and Community Services: A Primer* 12 (October 2000)(hereinafter "HCBS Primer").

<sup>13</sup> Medicaid's rehabilitation option allows states to provide a range of supportive services to people in home and community settings. Medicaid defines rehabilitation services as any medical or remedial services recommended by a physical for maximum reduction of a recipient to his or her best possible functional level. Rehabilitation services may be provided to people with either physical or mental disabilities. *Id.* at 11.

individuals waiting for these services<sup>14</sup> – a source of great frustration for consumers and family members:

*Waivers are not enough; they are limited in number and scope, and far too many people are languishing for years on waiting lists for them. My own grandfather died while awaiting proper supports to return him to his own home from the nursing home where he was stuck. -- Family Member, Written Public Comments.*

In describing the barriers to community living posed by institutional bias, HHS components identified ways that Medicaid eligibility rules foster reliance on institutional care. Many adults are ineligible for Medicaid until they are both poor and totally disabled. This means that by the time they are sick enough to qualify for Medicaid, they may not have the financial resources needed to pay for their rent and other basic needs. When care is provided in a nursing home, Medicaid's financial eligibility rules are more generous. For example, an individual can qualify for Medicaid in a nursing home with income up to 300 percent of the federal poverty level. Unless an exception is granted under a waiver, this rule generally does not apply to an individual who lives in the community.<sup>15</sup>

For married couples, if one spouse needs nursing home care, special rules protect the income and assets of the spouse who remains in the community up to certain limits. There are no financial protections, however, for a husband or wife if the spouse in need of care remains at home. Families who are caring for a disabled child face similar problems. Regardless of the specific eligibility group involved, generally, the parents' income is not counted in determining Medicaid eligibility for a child if the child is placed in an institution. In contrast, family income is counted to determine Medicaid eligibility if the family cares for their child at home. This means that to get help, many families have no choice but to institutionalize their child.<sup>16</sup>

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<sup>14</sup> For example, one study estimates that between 80,000 and 200,000 individuals with developmental disabilities experience significant delays in receiving services because these individuals are on waiting lists for care. Gary Smith, *Closing the Gap – Addressing the Needs of People with Developmental Disabilities Waiting for Supports*, National Association of State Directors of Developmental Disabilities Services (1999). Further, the evidence suggests that pressure on waiting lists will intensify as the population changes. Arlene S. Bierman et al., *Assessing Access as a First Step Toward Improving the Quality of Care for Very Old Adults*, J Ambulatory Care Manage (reprinted by AHCPR 1998).

<sup>15</sup> Studies confirm that eligibility rules, such as financial eligibility requirements for personal care that are more stringent than requirements for institutional care, contribute to institutional bias. See Harrington, et al.; Williams.

<sup>16</sup> The Katie Beckett or TEFRA option, enacted in 1982, enables states to provide Medicaid to certain children with disabilities living at home who need extensive care but who, without the option, would be unable to qualify because their parents' income or resources put them above the financial eligibility cutoff. The TEFRA option is limited in the following ways. First, home care for the child must be appropriate. Second, the estimated cost of community services for the child may not exceed the cost of institutional care. Third, the child must require the level of care normally provided in an institution, making the TEFRA option unavailable to children whose disabilities do not require this level of care. The Katie Beckett option is available in 19 states.

*Ever since [my son] was born our family has not been serviced properly by the agencies who are supposed to provide us with what we need to keep him at home. Yet, if we decide to place [my son] in an out-of-home placement center these same agencies have no problem funding the vendors/caregivers who operate the home ... My question to you is, 'Why can't the money follow the child?' As an involved parent, I know my child better than anyone. I know his wants and needs. So, why go through such great expense by hiring an outside person to replace the irreplaceable – an involved parent. -- Family Member, Written Public Comments.*

*I find it difficult to fathom why the states are willing to pay for me to place my son in an institution, paying several times over what it would cost for me to care for him, and yet not help me and my family financially to care for my son in the best environment for our son--our home. -- Family Member, Written Public Comments.*

States share the view that the structure of Medicaid favors institutional care. They point out that because nursing facility services are required, optional “home and community-based services are more at risk in times of budget problems than nursing home care.” Further, they view institutional bias in Medicaid as antithetical to the *Olmstead* decision and a major impediment to compliance with the Americans with Disabilities Act.

*Both Medicare and Medicaid are fraught with institutional bias. Given the clear language in the Americans with Disabilities Act (ADA) and the Supreme Court's language in Olmstead . . . this bias needs to be eliminated and replaced with bias (or presumption) that places home and community-based options as the presumptively preferred ones and makes institutional options the choice of last resort. -- State Agency, Written Public Comments.*

## **2. Eligibility Restrictions**

Eligibility restrictions were identified as a significant barrier to access. As a general rule, individuals with disabilities must meet two types of eligibility requirements of a specific eligibility group in order to receive Medicaid benefits. Each eligibility group has financial (income and resource standards) and categorical (e.g., aged, blind, disabled) requirements.

One issue identified by numerous responders is the caps on income eligibility. In states that have not opted to allow applicants to spend down their income to the Medicaid income eligibility level, persons whose income exceeds Medicaid limits are ineligible for medical assistance. Yet, these individuals may have very low-incomes and may not be able to afford the care they need. Individuals with disabilities and their families describe these caps as a “cliff without a safety net.”

*Having applied for Medicaid, [my son] was denied due to the meager \$330 a month [income limit] level. The cost of care for a brain-injured person is huge. . . .the \$330 [income limit] is a joke. It might just as well be \$3.30. It*

*will not make it. His disability income is fully utilized for partial room and board services . . . . This leaves [my son] in dire need of financial assistance for doctors, medications, disability services and sufficient room and board . . . his disability income won't even come close to their expenses.* – Family Member, National Listening Session

Although 35 states permit individuals to spend down their income on a periodic basis to meet financial eligibility requirements, the spend down levels may be so low that an individual is left with insufficient income to cover basic living expenses. For example, in 60 percent of states that provide services to persons who are “medically needy” (21 of 35), the medically needy income level is below the level for Supplemental Security Income (SSI) benefits (currently \$512 a month for an individual). Of those 21 states, seven have levels that are less than 50 percent of the SSI rate. A new federal rule promulgated last year gives spend down states the option to allow individuals to meet the spend down level while retaining more of their income for basic necessities,<sup>17</sup> but few states have chosen this option.

*I have concerns about my employee, a person with a significant disability who has chosen to live in the community. . . . She has a small amount of unearned income, which is supplemented by Social Security and income from her part-time job. She is an excellent employee, well liked by her co-workers, and very productive. But she needs attendant care to get out of bed in the morning and get dressed for work. . . . Due to the small amount of unearned income, she does not qualify for any program that would help her get attendant services. The spend down required to be able to buy into Medic[aid] is excessive. If she bought into Medic[aid], she'd lose her home. Her income is going to pay her mortgage and pay for and support her van which is necessary to get to work, to medical services, get groceries, etc. She has been paying for attendant care services out of pocket, but that eats into her income so she isn't able to purchase assistive aids that she needs for continued independence as her disability progresses. --*  
Consumer/Employer, Written Public Comments.

## **B. Medicare**

Since 1972, Medicare has covered people under age 65 who have received Social Security Disability Insurance benefits for at least 24 months. Today, Medicare covers about 5 million people under age 65 with disabilities, a number which is expected to grow to more than 9 million by 2020. HHS components and public respondents identified barriers related to the Medicare program.

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<sup>17</sup> 42 C.F.R. Section 435.1007.

## 1. Medicare Home Health Restrictions

One of the most important Medicare benefits for individuals with disabilities is home health care. Approximately 3 million Medicare beneficiaries receive home health services, receiving an average of 80 home health visits per year. Sixty-six percent of Medicare home health users are aged 75 and older, and 25 percent of Medicare home health users are aged 85 and older.<sup>18</sup>

Medicare covers part-time or intermittent skilled nursing care and home health aides, physical therapy, speech language pathology and occupational therapy for as long as a doctor prescribes it, medical social services, certain medical supplies and medical equipment in the community. To qualify for these services, an individual must meet statutory eligibility criteria.

One of Medicaid's statutory criteria is that eligible individuals must be "homebound." The homebound requirement was identified as a significant barrier to community living by HHS components and in written comments by 55 individuals and organizations representing consumers, family members, providers and state officials. Individuals emphasized how difficult this requirement made community living since, in effect, people become "prisoners in their own homes."

*I'm a C-7 Quad. I'm 34 and I live alone in Livingston Co. KY. I was 22 when I was injured. I had a good paying job when I was hurt. . . . My doctor put me on homebound so I can get a health care aid to help me with my showers and other bathroom needs. I am told by my care-giver that I'm not to leave my home. I can't date, go to college even though I got a scholarship. I can't better myself because of homebound rules. I could be working and paying taxes if these rules were not so strict. – Consumer, Written Public Comments.*

*I work with two young men who are both quadriplegic. Both have been married and divorced. They constantly tell me of how they miss interacting with people due to the homebound rule. They both want to be in a relationship but have no opportunity to do so since they are primarily at home. Both have transportation available but can't drive as they would be removed from services. One has a son who is very active in sports. This father can not be a father due to the restrictions in place. If he was caught attending his son's baseball game, he would be dropped from the program which he needs. This has happened to several people I know already. The sad thing is that often when people acquire a disability, some give up. But there is a small percentage who wish to continue on with their life. They have dreams, goals and wishes for the future. All of which are discouraged because of needing 6-8 hours of help a week. -- Provider, Written Public Comments.*

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<sup>18</sup> Who Uses Medicare's Home Health Benefit? AARP Public Policy Institute (1998).

## 2. Medicare Durable Medical Equipment (DME) Restrictions

Another concern identified by public respondents is how the Medicare program authorizes payment for durable medical equipment (DME) (wheelchairs, canes, walkers, etc.). Currently the Medicare program will purchase or rent DME to be “used in the patient’s home.” Considerable concern was expressed by public respondents that if coverage of DME is restricted to items used only “in the patient’s home” then it does not support the full integration of people with disabilities in their own communities. A second concern raised by HHS components is that Medicare coverage for DME is not available prior to discharge. Thus, hospitalized or institutionalized individuals have little or no opportunity to learn how to use needed equipment before being discharged to the community.

*When the guidelines only cover a wheelchair that will allow you to be mobile within your home, how can you be a part of a community? . . . these as well as many other policies . . . discourage the young disabled from even trying to be really a productive community-based person. -- Family Member*

*We have an active caseload of about 1,000 clients, 40 percent to 50 percent of whom rely on Medicare . . . I, as an OT [Occupational Therapist] incorporate best practices outlined by American OT Association into my clinical practice . . . However, current Medicare policy creates a clinical dilemma for myself and other clinicians as well. Specifically we have to choose between our professional experience and ethical obligations to make the mobility device recommendations functional for them or make recommendation that will satisfy the Medicare limitations on mobility device coverage. . . . If I follow best practices, then I will recommend devices that will support the highest level of independence but may not be affordable to the person should they choose to purchase it on their own. If I tailor my policy to Medicare policies, I’m limited to recommending equipment which will allow the client to get around within the four walls of their home only. Medicare policy shouldn’t force such a choice on people. Public policies [should] somehow complement each other and strive toward the same goals . . . Current interpretation use by the CMS and the DMERC [Durable Medical Equipment Regional Carrier] [are] significantly limiting access to community services for people with disabilities. – Provider, National Listening Session.*

### C. Array of Services

HHS components and public respondents identified numerous service gaps and unmet needs affecting various populations. Although lack of funding was identified as a major reason why specific services are lacking or lacking in sufficient quantity, other respondents identified service gaps resulting from the allocation of resources and the structural impediments within existing programs.

## 1. Persons with Mental Illnesses

One of the most serious gaps identified by respondents was the inadequacy of mental health and substance abuse services. Indeed, as a report prepared for SAMHSA's Center for Mental Health Services recently observed, a variety of "persistent clinical, service system and financial barriers" have contributed to the continued institutionalization of tens of thousands of individuals with serious mental illness, despite the fact that a "wealth of research and service knowledge" exists regarding effective means of helping people with serious mental illness achieve and maintain stable community living.<sup>19</sup> Specifically, this report notes that individuals with mental illness lack access to appropriate trauma care, new antipsychotic medications, treatment for co-occurring disorders, and services for general and mental health.<sup>20</sup> A similar report regarding the need for community-based care for children with emotional disturbance found that "[s]adly, there are few places in the United States where availability and use of mental health services [for these children] approach the level of need."<sup>21</sup> This report identifies clinical, service fragmentation and financial barriers to care for children with emotional disturbance, and describes the often bleak results for children who need adequate community care but do not receive it.<sup>22</sup>

In order to understand why Medicaid payment is so limited for people with serious mental illness, it is important to understand that mental health treatment is not a category of coverage in the Medicaid program. Instead, coverage of mental health treatment is a patchwork of Medicaid mandatory services, such as physician services as well as optional services such as prescription drugs and the clinic, rehabilitation and personal care options.

*Many federal programs are a lifeline or should be a lifeline for people with mental illness, but it turns out these are mostly not mental health programs, per se; and the mental health component of each program is relatively small potatoes, and tends to get isolated and we think, inadequate attention. For example, Medicaid is the largest federal mental health program, although depending on how you count*

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<sup>19</sup> Advocates for Human Potential, *Overcoming Barriers to Community Integration for People with Mental Illness* (2001) (hereafter "Overcoming Barriers"). This report also describes potential solutions to the problems it identifies.

<sup>20</sup> *Overcoming Barriers*. Other studies have also documented that lack of coordination has a negative impact on the quality and effectiveness of treatment for individuals with co-occurring mental health and substance abuse disorders. William Moran et al., *Services to Persons with Co-occurring Mental Health and Substance Abuse Disorders – Provider Perspectives – Program Descriptions*, Office of Inspector General, U.S. Department of Health and Human Services (1994).

<sup>21</sup> Advocates for Human Potential, *Overcoming Barriers to Serving Our Children in the Community* (2001) (hereafter "Serving Our Children").

<sup>22</sup> *Serving Our Children*. This report also describes a variety of solutions and best practices to address these problems.



*mental health costs are only 5 to 10 percent of Medicaid.* -- National Association, National Listening Session.

Another barrier is the effect of the statutory exclusion on Medicaid payments for care in an Institution for Mental Diseases (IMD) and how this exclusion works in conjunction with the cost effectiveness requirements of Medicaid waivers to limit the availability of HCBS waiver services to adults with serious mental illness. Title XIX of the Social Security Act prohibits federal payments for persons 21 to 65 years of age residing in an IMD. Thus, there are few federal dollars supporting people with serious mental illness in state psychiatric hospitals. Under Medicaid home and community-based waivers, states can provide home and community-based care to individuals as an alternative to institutional placement but the state must demonstrate that the program will be cost neutral to the federal government. Since historically, few federal dollars have flowed to institutions that provide care to people with serious mental illness, states generally have not succeeded in obtaining approval of waiver programs for people with serious mental illness. Studies document that many policy makers have long regarded the IMD exclusion as a barrier to community-based care for individuals with mental illness,<sup>23</sup> as comments received during the public input process reflect.

*We are not asking you to rescind [the IMD]. However, I would like to point out that what has happened over the course of time dating back to the 1960's is that without Medicaid reimbursement for these services that has put us further behind with respect to Medicaid reimbursement in general and has made it very, very difficult for us to use the federal waiver programs because we can't cap out of something we didn't have.* -- State Agency, National Listening Session.

For children with serious emotional disturbances, the lack of compliance with the requirements of Medicaid's Early, Periodic, Screening, Diagnosis and Treatment Program (EPSDT) is another major concern.

*One of the required benefits of the Medicaid Program is Early Periodic Screening, Diagnosis and Treatment (EPSDT). This benefit requires that children be periodically screened for their physical and mental health needs. If a diagnosis is discovered, the state must pay for treatment, regardless of whether or not the diagnosis is covered in the Medicaid plan. While this benefit has great potential to help children, especially those with mental health needs, it has not been well implemented or enforced. In 1996, only 37 percent of the 22.9 million children eligible for EPSDT received a medical screening through the program. This has implications for the State Children's Health Insurance Program as well, since the Medicaid expansion*

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<sup>23</sup> Overcoming Barriers.

*method is one of the three types of programs that states can adopt. -*  
- National Association, Written Public Comments.

Respondents also identified the need to improve funding flexibility in block grant programs that pay for services for individuals with mental illness and substance abuse.

*Currently, inflexible rules governing expenditure of mental health and substance abuse block grant funds bar states from adequately investing in services targeted to individuals with mental illnesses and co-occurring substance abuse disorders. Numerous peer-reviewed studies have demonstrated that integrated treatment (as opposed to parallel and sequential treatment) is most effective in serving persons with co-occurring mental illness and addictive disorders. --*  
National Association, Written Public Comments.

Individuals with co-occurring mental illness and addiction disorders face additional barriers. This population, estimated to include approximately 10 million to 12 million Americans, are at great risk for being institutionalized, incarcerated and homeless. Research amassed over the past 10 years and summarized in 1999 in the Surgeon General's Report on Mental Health<sup>24</sup> supports a shift to treatment that combines interventions directed simultaneously to both conditions by the same providers. According to the Surgeon General's report, combined treatment is effective at engaging people with both diagnoses in outpatient services, maintaining continuity and consistency of care, reducing hospitalization and decreasing substance abuse while, at the same time, improving social functioning. Yet, access to such combined treatment remains limited.

One result of the lack of adequate treatment for adults with mental illness and co-occurring substance abuse disorders has been the transinstitutionalization of these individuals from the mental health system to the criminal justice system.<sup>25</sup> A report by the United States Department of Justice (DOJ) indicated that approximately 283,800 people with mental illness are confined in local jails and state and federal prisons.<sup>26</sup> Respondents to the HHS public input process also articulated this problem.

*Most people with mental illness are released from jail without income support (SSI/SSDI) or medical benefits (Medicaid/Medicare) resulting in frequent decompensation and re-arrest. –* National Association, Written Public Comments.

*Prisons have become the institutional home of growing numbers of people with severe mental illness. Community services for these*

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<sup>24</sup> Mental Health: A Report of the Surgeon General (1999).

<sup>25</sup> Linda Teplin, The Criminalization of the Mentally Ill: Speculation in Search of Data, Psychological Bulletin 94:54-67 (1983).

<sup>26</sup> Paula Ditton, Mental Health and Treatment of Inmates and Probationers, U.S. Department of Justice, Bureau of Justice Statistics Special Report (1999).

*people have been inadequate, causing them to get entangled with the legal system. -- State Advisory Board*

In addition, respondents criticized the lack of parity between treatment for mental health disorders and physical disorders in Medicare.

*Medicare covers fewer days for hospitalizations for mental illness than for other hospitalizations. Inadequate treatment of a mental illness may lead to further institutionalization. -- State Agency, Written Public Comments.*

*Medicare pays only 50 percent of the allowed amount for mental health services, whereas for other services Medicare pays 80 percent of the allowed amount. Consumers with limited incomes may forgo treatment. When mental health problems are left untreated they can escalate and result in institutionalization. -- State Agency, Written Public Comments.*

Finally, many respondents identified stigma and prejudice as a continuing barrier to appropriate treatment for adults and children with serious mental illness.

*In order for individuals with disabilities to be afforded the same opportunities as the majority of the population, barriers such as lack of self-esteem and lack of opportunities due to discrimination and stereotyping attitudes need to be addressed. -- State Agency, National Listening Session.*

*. . . [A]ddress the issues of discrimination [for persons with mental illness] -- Researcher, National Listening Session.*

*Education and outreach efforts should be made available to dispel some of the myths. -- Consumer/National Association, National Listening Session.*

*Too many public mental health programs treat people with psychiatric disabilities like the proverbial glass that is half, or a third, or a tenth full - or completely empty! Providers become stuck in their negative view of the consumer because they have too much information about the problem and not enough information about strengths and solutions. No one survives with a mental illness without developing some strengths. --- Advocate, Written Public Comments.*

## 2. Racial and Ethnic Minorities

Many respondents noted that targeting specific populations for receipt of services results in inequity across populations, which in turn causes some groups to receive inadequate services. Public respondents raised a passionate plea for attention to issues of discrimination and the need to ensure that people with physical and mental disabilities who are members of racial and ethnic minority groups have access to treatment that is culturally appropriate and linguistically accessible.

*I would like to talk a tiny bit about disparities. African Americans have proven to have less than one percent of the resources, even that little bit that's given to the consumer movement. We run nothing, we have nothing, and we are not provided the necessary technical assistance that our numbers warrant. -- Consumer, National Listening Session.*

*There are also communication accessibility barriers. This could be interpreter services or translator services for people without disabilities who speak a different language. -- National Association, National Listening Session.*

HHS' Office of Minority Health (OMH) identified the need for culturally and linguistically appropriate services for minority individuals with disabilities and their families. In addition, the Administration for Children and Families (ACF) reported that although refugees with disabilities qualify for the same programs and services as American citizens with disabilities, refugees with disabilities who have limited English proficiency are often denied access to programs and services intended for people with disabilities because of language barriers.

A review of existing literature further evidences the need for culturally and linguistically appropriate health and social services. For example, a study examining the delivery of services to older individuals of color (including African Americans, Hispanics, Asian Americans and Pacific Islanders and American Indians and Alaska Natives) identified such barriers as the inability to speak English, lack of bilingual and bicultural staff, cultural differences that associate stigma with the receipt of public services, and distrust of service providers.<sup>27</sup> Language differences, distrust of medical providers and stigma were also identified as major barriers to services for individuals with HIV/AIDS who are members of racial and ethnic minority groups.<sup>28</sup>

In addition, in an August 2001 report, the U.S. Surgeon General described disparities in and barriers to adequate mental health care for members of racial and ethnic minority

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<sup>27</sup> American Society on Aging, *Serving Elders of Color: Challenges to providers and the Aging Network*, Administration on Aging, U.S. Department of Health and Human Services (1992).

<sup>28</sup> Health Resources and Services Administration HIV/AIDS Bureau, *Delivering HIV Services to Vulnerable Populations: What Have We Learned?* (Report #6), U.S. Department of Health and Human Services (2000).

groups.<sup>29</sup> The Surgeon General examined mental health issues for four groups of racial and ethnic minorities: (1) African Americans; (2) American Indians and Alaska Natives; (3) Asian Americans and Pacific Islanders; and (4) Hispanic Americans, and described significant disparities in the access, quality and availability of mental health services for these populations. For example, the report states that African Americans with mental health needs are unlikely to receive treatment and more likely to be incorrectly diagnosed than white Americans. The report describes American Indians and Alaska Natives as suffering “a disproportionate burden of mental health problems compared with other Americans.”<sup>30</sup>

Further, the report found that Asian Americans and Pacific Islanders have the lowest utilization of mental health services among ethnic populations, and describes a general failure to provide mental health services for the “vast majority” of Latinos who need it, including an “especially pronounced” failure to provide care for immigrant Latinos. The report identifies the “foremost barriers” to mental health care for minority individuals as the cost of care, the societal stigma of mental illness, and the fragmented organization of services. The report also concluded, however, that “disparities also stem from minorities’ historical and present day struggles with racism and discrimination, which affect their mental health and contribute to their lower economic, social and political status.”<sup>31</sup> A 1999 report of the Surgeon General found that minority children experience premature terminations of mental health services and poverty-related shorter lengths of stay in treatment programs on a more frequent basis than their majority counterparts.<sup>32</sup> Among other findings, this report noted that African-American youth access inpatient care at a higher rate than their numbers would predict, and that these youth are disproportionately represented in child welfare and juvenile justice systems, as well as in special education programs for children with emotional disturbance.<sup>33</sup>

American Indians and Alaska Natives (AI/AN) with disabilities also confront unique barriers to community integration services due to lack of cultural sensitivity and inadequate resources targeted to rural communities and reservations. Data indicates that more than 26 percent of the AI/AN population lives with a significant disability, with tribal leaders reporting that diabetes, alcohol and substance abuse and injuries at crisis proportions in their communities. In addition, many other AI/AN individuals experience the effects of less severe disabilities.

The prevalence of these disabilities and the obstacles they pose to community integration was noted by both the Indian Health Service (IHS) and the Office for Intergovernmental Affairs (IGA). IHS reported that support services for AI/AN individuals

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<sup>29</sup> Office of the Surgeon General, *Mental Health: Culture, Race and Ethnicity: A Report of the Surgeon General*, U.S. Department of Health and Human Services (2001) (hereafter “*Mental Health: Culture, Race and Ethnicity*”).

<sup>30</sup> *Mental Health: Culture, Race and Ethnicity*.

<sup>31</sup> *Mental Health: Culture, Race and Ethnicity*.

<sup>32</sup> *Serving Our Children* (describing findings of *Mental Health: A Report of the Surgeon General*).

<sup>33</sup> *Serving Our Children* (describing findings of *Mental Health: A Report of the Surgeon General*).

with disabilities are generally lacking. In addition, the IHS indicated that issues affecting this population are made more complex by the great need for assistance and the sovereign status of more than 500 tribal governments. IHS reported that many AI/AN individuals with disabilities are institutionalized due to an inadequate supply of home and reservation-based services, resulting in part from an inadequate utilization of the Medicaid home and community-based waiver program.

Specific barriers to community integration for AI/AN individuals with disabilities include inadequate resources to support the needs of AI/AN individuals with mental disabilities and insufficient home and community-based services for AI/AN elderly individuals, including those with disabilities. The lack of adequate foster care programs for AI/AN children with special needs poses a barrier to these children's ability to receive care and services in the most integrated setting, because without these services, AI/AN children with disabilities are more likely to be placed in less home-like, more restrictive care settings. Other barriers include a lack of providers or resources to meet the needs of individuals who require special devices to assist with their activities of daily living, and the lack of knowledgeable practitioners to diagnose and treat Fetal Alcohol Syndrome and children's mental illness.

Public comments mirror IHS' concerns:

*And a lot of types of service providers do not know how to work with us. They use excuses about language, culture and how far and remote we are. . . . There is a lack of outreach and services and in some instances there are no services. The issues that come up are the vast distances, the lack of cultural awareness and not enough money to get out to the reservations. -- National Organization, National Listening Session.*

*Funding and the lack of technical assistance to build rehabilitation programs and independent living centers are scarce on our reservation. Agencies that provide these services do so to the general population but the services do not extend to the Indian reservation. -- Advocate, National Listening Session.*

### **3. Rural Populations**

Barriers related to the inaccessibility of necessary services are often exacerbated for individuals with disabilities who live in rural areas.<sup>34</sup> Rural residents have experienced decreased access to health services and experience poorer health and social welfare outcomes.<sup>35</sup> These disparities arise in part from the fact that certain

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<sup>34</sup> C. Neil Bull et al., *Challenges and Solutions to the Provision of Programs and Services to Rural Elders*, University of Missouri-Kansas City Center on Aging Studies (1991).

<sup>35</sup> HHS Initiative on Rural Communities Task Report (draft October 2001) (hereafter "Rural Communities Task Force Report"). This report indicated that the inadequate provision of certain services, including mental health and substance abuse treatment, account for some of the most stark disparities between rural and urban health

services simply may not exist in rural communities.<sup>36</sup> For example, one recent study indicated that rural communities may be the last areas to receive advances in mental health care, such as newer antipsychotic medications or specialized treatment programs.<sup>37</sup> Many rural residents may also lack access to care because they do not have the income to pay for health and social services.<sup>38</sup>

#### **4. Children and Adolescents**

The Administration for Children and Families (ACF) and the Indian Health Service (IHS) identified the lack of adequate foster care programs for children with disabilities as a barrier to community integration for these children. As ACF noted, children with disabilities may be more likely to be placed in institutional care because of an inability to access foster care placements in less restrictive settings. Similarly, the Substance Abuse and Mental Health Services Administration (SAMHSA) noted that children with serious emotional disturbances face obstacles to community integration when they experience multiple placements (such as residential treatment centers, hospitals, group homes, and therapeutic and standard foster care) within a short period of time.

SAMHSA also identified numerous barriers affecting the educational opportunities of children with serious emotional disturbances and other behavioral disorders. The Health Resources and Services Administration (HRSA) identified barriers specific to children with special health care needs, *i.e.*, children who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who require health and related services of a type or amount beyond that required by their peers. HRSA reported that barriers to community integration for these children include lack of access to comprehensive, family-centered, community-based medical care, lack of access to affordable health care, lack of access to early and continuous screening for special health care needs and inadequacies in family partnership and satisfaction. HRSA also noted that the disproportionate representation of children with disabilities in the juvenile justice system is due in part to inadequate community-based services.

Another service gap identified by HRSA is that there are few coordinated services available to assist children with special health care needs in successfully making the transition from school to post-school life, to independent living, and to the adult health and services systems. Similarly, SAMHSA described youth with serious emotional disorders as being caught between child and adult mental health systems and contending with fragmented service systems. Research confirms that service fragmentation impedes families' ability to obtain integrated, community-based care for children with disabilities. For example, a recent report prepared for SAMHSA's Center for Mental Health Services found that "[i]n many places serious gaps in

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and social services.

<sup>36</sup> Rural Communities Task Force Report.

<sup>37</sup> Overcoming Barriers.

<sup>38</sup> Rural Communities Task Force Report.

services [for children with emotional disorders] are a continuing problem,” and that “[t]he impact of these gaps is exacerbated by the lack of interagency coordination, diminishing the effectiveness of individual service components and leading to fragmentation and poor outcomes.”<sup>39</sup>

Public respondents also expressed concerns about the gap in services for adolescents and young adults who are aging out of school-based care systems.

*I am writing this letter to inform you about the services that are provided verses the services that my son . . . so desperately needs. . . [He] has a severe speech disorder and is also diagnosed with Cerebral Palsy. He is 24 years old and people that know him find him to be an extremely intelligent young man. . . . Since his graduation three years ago all the great services have been taken away from him. . . . It has been impossible to get appropriate services for [him] in speech. Medicaid only allows him to be seen in a clinical setting. Working alone on articulation or in a group behind closed doors is not what [he] needs. He needs to learn to communicate in the community so he can have as independent of a life as possible. -- Family member, Written Public Comments.*

*. . . I work with people transitioning from the education system to the adult service system. The transition process for families is quite difficult, as the adult service system is very different to navigate compared to the education system. People with disabilities have supports in school, then come out of school and placed on waiting lists, while they lose skills. – Advocate/Provider, Written Public Comments.*

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<sup>39</sup> Serving Our Children; see also Health Resources and Services Administration, Achieving Success for All Children with Special Health Care Needs: A 10-Year Action Plan to Accompany Healthy People 2010, U.S. Department of Health and Human Services (2001) (finding that a lack of service coordination impacts negatively on both the quality and effectiveness of treatment for children). Similarly, a report prepared for the Federal Interagency Coordinating Council concerning services for young children with disabilities concluded that current federal program requirements could require communities to respond to five separate needs assessments, requested at different times, all seeking similar information with a slightly different focus. Georgetown University Center for Child Health and Mental Health Policy, Building Integrated and Effective Services in the Community for Young Children and Their Families: Perceived Barriers Within Federal Legislation and Regulations (A Working Draft) (2000).



## **5. Transition Services**

Another service gap identified by HHS components and public respondents is the inability to secure timely assistance to support transitions when a person moves from one service system to another. For an individual moving from an institutional setting to the community, transition services and supports include rental deposits, first month's rent, training, counseling, furniture and other basic household items, personal care services, and other supports that would allow an individual to establish their living arrangements and work in the community. These services must not only be available, they must be coordinated to coincide with provision of longer term supports and housing.

CMS noted that services and resources are inadequate to assist individuals in making the transition from living in a nursing home to living in the community, and CDC made similar observations. HRSA reported that there are inadequate resources to assist incarcerated adults and youth with disabilities to make a successful transition after their release.

## **6. Workforce Shortages**

HHS components acknowledged that personal care services are essential to the well-being of many individuals with disabilities. Components noted, however, that the current system of personal care in the community is negatively affected by modest reimbursement rates for staff, coupled with little professional organization and formal training. Recruitment and retention of these workers is difficult. As a result, there are far fewer personal care workers than are needed to meet the demand, and the capacity and quality of community services may be limited. These problems are also documented in recent studies. For example, low pay and lack of training for community-based mental health staff have been identified as "significant barriers" to the creation of appropriate residential and treatment programs for individuals with mental illness.<sup>40</sup> Without sufficient direct care staff in the community, individuals who are institutionalized but who could be appropriately served in the community are unable to leave the institution. Moreover, staff shortages and other inadequacies may place individuals who are currently in the community at risk of returning to institutional care.

The shortage of paid caregivers was a key concern expressed by many public respondents. Many attributed the shortage of direct care workers to inadequate pay, inequities between the rates paid to institutional workers versus community workers, lack of benefits, and lack of training for these individuals.

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<sup>40</sup> Overcoming Barriers.

*There is a massive shortage of hands-on workers to provide services and support. – Advocate, National Listening Session.*

*Regardless of the state or region, community workers are expected to do their jobs at poverty level wages often without proper wages or employment benefits or with little or no opportunity for advancement. Not surprisingly, there's an ever increasing shortage of these workers. -- National Association, National Listening Session.*

## **7. Limited Access to Assistive Technology**

Almost 70 respondents identified barriers specifically related to assistive technology. The most commonly identified barrier to accessing assistive technology was the lack of a dedicated funding stream and technology transfer program to connect people with the devices they need. Another factor frequently identified was the restrictive definitions used by the federal government for “medical care,” “medical necessity,” and “durable medical equipment.” Research confirms that these definitions result in barriers to community integration and provide support for the view that they should be updated.<sup>41</sup> Many individuals highlighted the restricted definitions of reimbursable devices and emphasized the cost savings that the states and federal government would experience if they would fund a wider range of devices. For example, for \$30 a month, one provider wrote that he purchased a cell phone for a consumer that helped him to establish a natural support network and to engage in community activities whenever he wanted without the help of a paid caregiver. Then the Department of Disability Services determined that the cell phone was not medically necessary. Now, this consumer can only access the community with the help of paid staff at a monthly cost of \$300, ten times the cost of the cell phone.

For many consumers, lack of access to assistive technology prevents them from attaining self-sufficiency.

*Many Americans with post polio syndrome would like to work again or continue working. Our greatest challenge is not the job itself but getting from the job, getting from home to the job. Insurance companies do not pay for chair lifts, ramps, batteries to operate mechanical devices to get to work. These are very expensive and cost a lot of money. -- National Association, National Listening Session.*

*One of the people before talked about getting a replacement wheelchair. He could be totally independent during the day if he had a power chair. The regulations, rules and things, he's been waiting for two years for that chair. He can't get a job. He can't do anything regularly. He can't make plans because he doesn't know if he'll have someone to push him. --Provider, National Listening Session.*

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<sup>41</sup> National Council on Disability, Federal Policy Barriers to Assistive Technology (2000).

## Responsiveness of Services to Meet Individual Needs

Both HHS components and many public respondents believe that Medicaid should become a more person-centered program. As both HHS components and respondents noted, and as described above, dollars in the Medicaid program largely flow to specific providers to serve specific populations, generally defined by age or diagnostic criteria, in specific environments with a specific package of services. Medicaid's eligibility rules for persons with disabilities have been described as "extraordinarily" complex, making it difficult for persons with disabilities to complete application requirements and procedures and for state Medicaid officials to administer the program.<sup>42</sup> Eligibility rules and budget neutrality requirements restrict access to narrowly defined and targeted populations.<sup>43</sup> This categorical approach was criticized by state and local government entities, consumers, advocates and families as too rigid and inflexible. For example, one respondent described the problems faced by a family that wanted to modify their home with a ramp and to purchase a lift for their van so they could keep their daughter living with them. Due to a cap on the dollar amount that can be spent each year on home and vehicle modification, however, the family could not do both in one year. The family wanted to use Medicaid dollars set aside for another purpose -- respite hours -- to make the needed modifications at the same time. This flexibility was not allowed, however, and without both vehicle and home modification the daughter will have to be institutionalized because the family cannot transport her out of their home.

This and other public input suggest that Medicaid structure and financing has driven development of a service delivery system that often does not meet the needs of people with disabilities. For example, inflexible Medicaid categories result in people with similar levels of need obtaining vastly disparate levels of service. One group in this category is individuals who have become disabled due to traumatic brain injury (TBI). Only 22 states have waivers to service individuals with TBI, and these are limited. Individuals who suffer traumatic brain injury as adults (over age 21) find there are few, if any, programs available to address their needs.

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<sup>42</sup> Andy Schneider et al., Medicaid Eligibility for Individuals with Disabilities, Kaiser Commission on Medicaid and the Uninsured (Undated).

<sup>43</sup> Cost-Effectiveness of Home and Community-Based Long-Term Care Services, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services (1999).

*I would like to point out the lack of community life, financial assistance for traumatically brain injured individuals. My son is totally disabled with a brain injury. He will not work again, never. . . . when you look at all the areas currently being funded, long-term care for the traumatic brain injured is not to be found. As I go around to the state agencies, there are many types of disabilities being funded. [My son] doesn't fit the development disability area, nor does he fit any other types of areas. Drug rehab, alcohol rehab, a lot of programs, but for a traumatic brain injury, TBI, it doesn't exist. -- Family Member, National Listening Session.*

*[My brother] was 23 when he had a motorcycle accident,. . . he could have been cared for under the MR/DD [Mental Retardation/Developmental Disabilities] waiver, had he not had his accident after the age of 22. But he's in between the MR/DD waiver and the Elderly waiver; there's a whole population of disabled people that are left out. -- Family Member, National Listening Session.*

Despite similar needs for support and treatment, individuals with certain types of disabilities that fall outside of the categorical designations either because they need a different amount or type of care or fail to meet the diagnostic criteria, have less access to the care they need than others.

Another problem is that under current Medicaid waiver regulations each home and community-based waiver can be targeted to one group.<sup>44</sup> This means that states must operate multiple waiver programs to serve people with disabilities in their own communities.

*The waiver system creates artificial parameters into which real people do not fit, and, therefore, do not get the services they need. They must choose between one waiver that satisfies some of their needs and another waiver that satisfies some different needs. Services should be tailor made. People should not be reduced to slots. -- Professional, National Listening Session.*

Today, states are managing 261 separate home and community-based waiver programs. Colorado, for example, operates 10 waiver programs: five distinct waiver programs for individuals with developmental disabilities, one for people with mental illness, one for individuals who have brain injury, one for persons with AIDS, one for the “elderly, blind and disabled,” and one for medically fragile children.<sup>45</sup> Each waiver requires a

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<sup>44</sup> HCBS waivers may only be targeted to one of the following target groups or subgroups: aged or disabled or both; mentally retarded or developmentally disabled, or both; or persons with mental illness. 42 C.F.R. Section 441.301(a)(6). In addition, as studies have found, maintaining the linkage between HCBS waiver eligibility and institutional care also prevents states from restricting access to nursing homes by imposing more stringent criteria for admission. See Harrington, et al.

<sup>45</sup> Gary Smith et al., *Understanding Medicaid Home and Community Services: A Primer*, George Washington university Center for Health Policy Research (2000)

separate application and often a separate administrative operation, and each must be renewed periodically. Although waivers are viewed as a critically important alternative to Medicaid-funded institutional care, respondents viewed the system as administratively burdensome, and difficult to negotiate and unresponsive to the needs of consumers and their families.

HHS components, families, consumers, their advocates and state agencies were clear about the need for a more flexible, person-centered approach, designed to meet the needs and preferences of each individual with a disability and to give individuals maximum control over how those services are delivered.

Consumer and family member respondents want more control and the ability to make choices about their lives and the services that they receive. Further, they view the ability to exercise control and choice over *what* services they receive and *where* they receive them as critical to health and recovery.

*The possibility that I will not have to suffer the anguish and despair of surrendering to the anonymity & uncertainties of institutionalized care, but may be given the option of more intimate or “familial” care in a residential setting, right in our home community, not only offers me hope, but may, in some cases, even prolong life itself. -- Consumer, Written Public Comments.*

*Fifteen years ago . . . I was basically . . . a bona fide Reaganomics 1980’s Cuisinart yuppie. But I became a disabled person . . . I lost everything. Now, I live at a poverty level on social security disability. . . I have a degenerative disease. It is progressive. It gets worse and it only goes in one direction. And I fear that if I can’t have attendant care when I need it in my home, I will be institutionalized. And what I will lose, then, it’s the last thing that I have. It’s my freedom. As much as I have lost to date, I still have more to lose. -- Advocate, National Listening Session.*

Importantly, state and local public authorities also cite the inflexibility of Medicaid program rules as an impediment to improving access to care in the community.

*Most states . . . would argue that they are strapped by the level of federal regulations that are in the program. -- State Agency, National Listening Session.*

Public input strongly suggests that using Medicaid dollars flexibly to meet individualized care needs would allow for the more efficient use of scarce resources and potentially could result in curtailing inappropriate and unnecessary institutionalization.

Public input also suggests strong, broad-based support to increase self-determination and consumer-directed initiatives that allow persons with disabilities and their families to

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control the dollars and have more choices about who provides services. Respondents including consumers, family members, providers, national associations and government officials believe that allocating funds to the individual (rather than a provider) will enhance the ability of people with disabilities to live in their own communities.

*The entire system must be redirected to be centered on persons with disabilities and their family. Systems must be structured in such a way as to fully allow for self-determination by people with disabilities. Funding should go to the consumer of services. -- National Association, National Listening Session.*

## Supports for Families and Informal Caregivers

There is little debate about the critical role that families and other informal caregivers play in supplying services to people with disabilities. Recent studies confirm that the vast majority of direct care (about 64 percent) is provided by families, friends, and neighbors. Among elderly persons needing assistance with activities of daily living, 95 percent have family members involved in their care. Women provide a significant majority of caregiving for individuals with disabilities. Among unpaid caregivers, the task generally falls to women as mothers, sisters and daughters of a person with special needs. If the work of informal caregivers had to be replaced by paid home care, the cost would be \$45-75 billion per year. However, the costs of caregivers – in terms of time, physical and emotional stress, and financial burden – are just as significant. A growing body of evidence confirms that the provision of supportive services can diminish caregiver burden, permit caregivers to remain in the workforce, and enable people with disabilities to remain in community settings - possibly delaying or avoiding institutionalization.

*I also want to recognize the growing number of family caregivers and other informal caregivers in our society. They are often the forgotten ones. But they are the major providers of care to older people in this country....They actually make up the largest component of our nation's caregiver workforce and will go to great lengths to keep their loved one at home. But they do so at great cost....Many families eventually burn out from this toll that this role takes on their personal and professional lives. The burden and breakdown of the family support system is often the key reason why an older person is placed in a nursing home. -- Family Member/Provider, National Listening Session.*

*Developing a partnership with family caregivers – which constitutes a huge private resource in the country – can save the government money because it will help families to extend the length of time they are able to help care for their loved one at home and in the community, thus lessening the time spent in more expensive forms of care, such as nursing homes and other*

*out of home placements.* -- Family Member/Provider, National Listening Session.

A number of respondents commented that while government programs often are unable or unwilling to provide them with supplemental help in the community, the same government programs will pay the full cost of institutional care.

*My own experience and research indicates that if a family institutionalizes its family member with a developmental disability, the government is willing to expend large amounts of taxpayer dollars to support this placement. On the other hand, if they decide to support their family member at home, the federal government sends them into a cycle often leading to poverty.* -- National Association, National Listening Session.

As noted in the previous chapter, HHS operates a number of programs designed to provide support to family caregivers. However, these programs, like Medicaid, base eligibility on categorical definitions that exclude many needy families. For example, the Administration on Aging (AoA) National Family Caregiver Support Program, by statute, provides support to family caregivers of older adults and to older family caregivers of children under the age of 19. The latter group is limited to grandparents who are the sole caregivers of grandchildren and those individuals who are affected by mental retardation or who have developmental disabilities. Family caregivers who are taking care of adults want the government to do more to recognize the important role they play and the sacrifices they have made to raise their children with disabilities in their own home.

*If we believe in helping the family stay together, if we believe in protecting the life of unborn children (regardless of their genetic makeup), if we believe that strong families are the backbone of this great country, then how can we say no to helping families that have special needs children care for their own children in their own homes with the least amount of stress and barriers to doing that.* -- Family Member, Written Public Comments.

*[We] encourage the Bush Administration to recognize the unique role of dedicated parents who are saving the taxpayers millions of dollars by preventing or postponing for as long as possible, out-of-home placement of their children.* – State Association, Written Public Comments.

Family members want help, not hand outs.

*I did not ask to have a child with a disability. I was given this child as a gift from God. I plan on doing the best I can. All I ask of you is to consider how the States and our nation might help me complete the assignment by removing as many barriers as possible.* -- Family Member, Written Public Comments.

*The families I've met don't want a "hand out" they want to be productive*

*working citizens. They just want to be sure that their child who needs special and expensive treatment will be provided for.* – Family Member, Written Public Comments.

## Fragmentation and Lack of Coordination

As noted above, the existing approach to financing long-term care services and supports results in compartmentalized programs. HHS components reported that individuals with disabilities face barriers to community living because the right “mix” of services and supports are rarely provided in one package. Instead, individuals with disabilities, their families and caregivers must cobble these supports together from multiple service programs, each of which may have its own funding streams, eligibility requirements, policies, procedures and service sites. There is no one place where individuals with disabilities in all target groups may (a) access timely, understandable information about their long-term care choices, and (b) apply for and receive all the services for which they are eligible. Consumers and their families are largely left on their own to try to understand and negotiate a very fragmented system. The continuing obstacles created by fragmented service systems is also documented in research. For example, a recent report focusing on barriers to care for individuals with mental illness identified a lack of coordination among community programs and services as “[p]erhaps the most difficult barrier to community integration” for this population.<sup>46</sup>

Public respondents offered numerous comments about the difficulty of accessing services in such a fragmented system. Consumers and their family members confront a daunting array of programs, each with its own rules, restrictions and administrative structures. They express frustration with the challenges of simply completing application forms and complying with onerous requirements such as face to face interviews. Negotiating these programs and trying to make them all fit, especially when consumers and their family members lack accurate information or need assistance to obtain information or to understand the information that has been provided very difficult.

*I am the single parent of two special needs children. I receive \$360 month[ly] child support. It took several years for me to learn that I even qualified for funding of any kind.* -- Family member, Written Public Comments.

*I was first told that I had to go to an office for my zip that requires three buses to get to and walking and standing which with joint involvement has been difficult even though the other office only required one bus to get to. I was told that when I got feeling better to come in and complete an application, even though I had no money. Found out after the fact that they*

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<sup>46</sup> Overcoming Barriers



*could have done a phone interview.* – Consumer, Written Public Comments.

Some respondents suggested that there was miscommunication among federal, state, and local programs, which often resulted in fragmentation of delivery of services. Because of duplicative efforts, the agencies were not providing the most efficient delivery of services. In addition, because programs are not always in tune with what others were providing, people with disabilities are not aware of program offerings and have a difficult time accessing information.

*Here....Medicaid runs several different programs. Unfortunately, each program does not know what the other program has; and therefore the consumers are lacking the information to what is provided by Medicaid, and that is my only concern, is that the communication of Medicaid between consumer and inter-departments is lacking. There needs to be an improvement between communication of Medicaid and also the training of the staff, not on just a federal level but also on the local level.* – Provider, National Teleconference.

HHS components acknowledge that individuals with disabilities and their families too often lack the information needed to access and effectively utilize services and supports that could facilitate community integration. For example, the Administration for Children and Families (ACF) noted that there is insufficient training and information for youth with disabilities in foster care placements to create and carry out plans to live in a community-based setting, as independently as possible. The Administration on Aging (AoA) reported that older adults and their families lack information about long-term care services. The Substance Abuse and Mental Health Services Administration (SAMHSA) identified a lack of awareness in the mental health community of relevant technologies for people with psychiatric and co-occurring disabilities.

The problem of fragmentation is exacerbated further because people with disabilities often must rely on services and support from multiple agencies and programs, including those that fall outside the jurisdiction of HHS. For example:

*In order for persons with psychiatric disabilities to receive the range of services needed to find and keep jobs, they must enroll in two different systems - Medicaid and Vocational Rehabilitation.* -- National Association, Written Public Comments.

Generally, public respondents felt there is little coordination between programs even when they serve the same or similar populations. Lack of coordination exists at the local, state and national level.

*The lack of coordination, cooperation, and integration at the federal level agencies created multi[ple] difficulties and barriers for persons with mental*

*illness, with or without substance abuse issues. . . . The absence of bringing together primary health care and mental health and substance abuse is a waste of resources and opportunities.* – Affiliation unknown, Written Public Comments.

HHS components also identified lack of coordination across federal agencies and programs as a barrier to community living. For example, SAMHSA reported that limited coordinated efforts among mental health, substance abuse, employment, and vocational rehabilitation providers creates unnecessary barriers that prevent individuals with psychiatric and co-occurring disabilities from attaining competitive jobs. SAMHSA, AoA, and other components that identified barriers in non-HHS programs such as housing, transportation and education generally noted that a contributing factor to these barriers is the lack of communication and coordination between federal agencies as to how they can work together to facilitate community integration.

The HHS self-evaluation revealed that some barriers result from the lack of a common definition of “disability” in eligibility and service criteria in federal programs. A 1996 GAO study identified more than 14 different definitions of disability used by federal programs alone and many of these definitions provided considerable agency and state discretion in eligibility determination. These differences among programs can make it extremely difficult for people with disabilities to access the full array of community supports they need. For example, a person with mental illness may need a guaranteed amount of monthly income to pay for medications and housing, in addition to job coaching, in order to remain successfully employed in the community. Job coach services, provided through the Department of Education define eligibility in terms of mental impairment or physical impairment; however, the Social Security Administration’s criteria for SSDI or SSI define disability in terms of an inability to work.

If the individual could more easily access prescription drug coverage through Medicaid and housing assistance through HUD they may not need the income provided by SSDI or SSI, but both HHS’ Medicaid program and HUD’s Section 8 Housing program have different means-testing and disability eligibility requirements. To become eligible for these programs, the individual would have to stop working, or significantly decrease the amount of money derived from working.

Moreover, federal laws authorizing or related to service development for individuals with disabilities have largely been shaped by the need for a particular set of services, some targeted for particular ages of people with disabilities or sub-populations of people with disabilities. The Rehabilitation Act of 1973 authorizes federal support for training and placing persons with mental and physical disabilities into full-time, part-time or supported employment. The Social Security Act of 1965 authorizes support to provide health care and income support for low-income persons with disabilities. The Housing Act of 1937 authorizes funds to assist low-income persons with disabilities and frail elderly obtain affordable housing. The statutes focus many agencies on providing a set of services (e.g., education, health, housing, income support) without an explicit program focus on the goal of community integration.

## Accountability and Legal Compliance

Respondents identified a need for greater federal oversight of programs that serve people with disabilities and stronger enforcement of laws that protect the rights of people with disabilities. They implored the federal government to ensure that all responsible authorities including the HHS Office for Civil Rights (OCR), the Department of Justice (DOJ), the Department of Housing and Urban Development (HUD) and other agencies have adequate resources and authority to fully enforce the laws that govern programs and protect people with disabilities from discrimination.

*I have a 19 year old with Autism. After moving to this state 6 years ago, it has been a constant battle to get services, and to this day, this state has refused to serve him ... that's the life story here, every agency always has an excuse of why they aren't responsible, and you get so frustrated, you just pay yourself, cause otherwise, you will never get it. I have court orders from the judge for him to get these services, and yet, he still never received them. -- Family member, Written Public Comments.*

*My friend . . . wants residential treatment but due to his need for personal treatment services and wheelchair accessibility, he has been refused by every rehab he has approached in our home state of Maryland. . . . For people with disabilities who have substance abuse problems, we beseech you, enforce the law. -- Consumer/Provider, National Listening Session.*

Public respondents also see a need for greater technical assistance and guidance to promote compliance with the *Olmstead* decision. They want greater federal guidance and help to assess and identify people with disabilities who are inappropriately institutionalized, and they want guidance on effective planning. Consumers, in particular, are seeking greater protection of their rights in the community to make their own choices and accept risk.

*We must do a better job of enforcing existing civil rights laws and do whatever is necessary to ensure quality and put an end to abuse. -- National Association, National Listening Session.*

*[S]tates need the flexibility and the funding to implement the *Olmstead* decision, but they also must be held accountable by the HHS Office of Civil Rights. -- Advocate, National Listening Session.*

Within HHS, the OCR identified a lack of coordination among HHS components and federal agencies as a barrier to accountability and compliance with the ADA and the *Olmstead* decision. With greater coordination, OCR noted, HHS could be more effective in

providing appropriate technical assistance to states, localities and others who need guidance in complying with their legal obligations.

Another barrier identified by HHS components is the lack of comparable data about persons with disabilities and their needs. Although data often exists at the state level, it is generally not quantifiable or comparable across systems.

## Conclusion

As the findings of this report demonstrate, there are numerous barriers that prevent persons with disabilities from full participation in American society. These barriers are not new. Barriers reflect issues that cut across programs and population groups, service access problems related to specific programs, and challenges with participating, living, and managing in the community.

Although lack of funding is a concern, many barriers exist due to the structure of programs that fund services, most notably Medicaid. Others stem from poor coordination between the various federal, state and local authorities, and the need to ensure that consumers and family members have better and more accurate information about available programs and services. Clearly, stakeholders are looking to the federal government to implement solutions to address these critical concerns.

Under the leadership of President Bush, this Administration is already doing much to address barriers to community integration. Executive Order 13217 makes clear, however, the President's recognition that barriers remain, and that it is only through coordinated federal agency action that community integration for people with disabilities will be achieved.

## Appendix B Acronyms

ACF	Administration for Children and Families
ADA	Americans with Disabilities Act
ADD	Administration on Developmental Disabilities
ADDGS	Alzheimer's Disease Demonstration Grants to States Program
ADLs	Activities of Daily Living
ADR	Alternative Dispute Resolution
AHRQ	Agency for Healthcare Research and Quality
AI/AN	American Indian and Alaska Native
AoA	Administration on Aging
ASBTF	Assistant Secretary for Budget, Technology and Finance
ASPA	Office of the Assistant Secretary for Public Affairs
ASPE	Office of the Assistant Secretary for Planning and Evaluation
BBA	Balanced Budget Act
BIPA	Benefits Improvement and Protection Act of 2000
CARE Act	Ryan White Comprehensive AIDS Resources Emergency Act
CCB	Child Care Bureau, within ACF
CDC	Centers for Disease Control and Prevention
CFR	Code of Federal Regulations
CMHS	Center for Mental Health Services, within SAMHSA
CMHSBG	Community Mental Health Services Performance Partnership Block Grant
CMS	Centers for Medicare & Medicaid Services
CMSO	Centers for Medicaid and State Operations, within CMS
CSAP	Center for Substance Abuse Prevention, within SAMHSA
CSAT	Center for Substance Abuse Treatment, within SAMHSA
CSP	Community Support Program

DD Developmental Disability

DME Durable Medical Equipment

DMEPOS Durable Medical Equipment, Prosthetics, Orthotics and Supplies

DOE Department of Education

DOJ Department of Justice

DOT Department of Transportation

EPSDT Early, Periodic, Screening, Diagnosis, and Treatment Program

FACA Federal Advisory Commission Act

FDA Food and Drug Administration

FFP Federal Financial Participation

GAO General Accounting Office

HCBS Home and Community-Based Services

HHS Department of Health and Human Services

HRSA Health Resources and Services Administration

HUD Department of Housing and Urban Development

ICS Institute and Centers, within NIH

ICCL Interagency Council on Community Living

ICF/MRs Intermediate Care Facilities for the Mentally Retarded

IDEA Individuals with Disabilities Education Act

IEP Individual Education Program

IGA Office of Intergovernmental Affairs

IHS Indian Health Service

IMD Institution for Mental Diseases

KDA Knowledge Development and Application Programs

MR Mental Retardation

NAPAS National Association of Protection and Advocacy Services

NCSL National Conference of State Legislatures

New FIG New Freedom Initiative Group

NF Nursing Facility

NCCAM National Institute of Complementary and Alternative Medicine, within NIH

NCI National Cancer Institute, within NIH

NCMRR National Center for Medical Rehabilitation Research, within NIH

NEI National Eye Institute, within NIH

NHLBI National Heart, Lung, and Blood Institute, within NIH

NIAMS National Institute of Arthritis and Musculoskeletal and Skin Diseases, within NIH

NICHHD National Institute of Child Health and Human Development, within NIH

NIDCD National Institute on Deafness and Other Communication Disorders, within NIH

NIDCR National Institute of Dental and Craniofacial Research, within NIH

NIDDK National Institute of Diabetes and Digestive and Kidney Diseases, within NIH

NIH National Institutes of Health

NIMH National Institute of Mental Health, within NIH

OAA Older Americans Act

OCR Office for Civil Rights

OCS Office of Community Services, within ACF

OFA Office of Family Assistance, within ACF

OGC Office of the General Council

OIG Office of Inspector General

OMH Office of Minority Health

OPHS Office of Public Health and Science

OPM Office of Personnel Management

OWH Office of Women's Health

P & A Protection and Advocacy Programs

PSC Program Support Center

SAMHSA Substance Abuse and Mental Health Services Administration

SAPTBG Substance Abuse Prevention and Treatment Performance Partnership Block Grant

SBA Small Business Administration

SCHIP State Children's Health Insurance Program

SNF Skilled Nursing Facility

SSA Social Security Administration  
SSDI Social Security Disability Insurance  
SSI Supplemental Security Income  
TAG Technical Advisory Group  
TANF Temporary Assistance for Needy Families  
TBI Traumatic Brain Injury  
TCE Targeted Capacity Expansion Programs  
VA Department of Veterans Affairs  
VICP National Vaccine Injury Compensation Program



## **Appendix C**

# **The Department of Health and Human Services: Component Descriptions**

### **ADMINISTRATION FOR CHILDREN AND FAMILIES (ACF)**

#### **AGENCY DESCRIPTION**

The Administration for Children and Families (ACF) is responsible for approximately 60 programs that provide services and assistance to needy children and families. ACF administers the state-federal welfare program, Temporary Assistance to Needy Families (TANF), the child support enforcement system, and the Head Start program. ACF provides funds to assist low income families in paying for child care and supports state programs that provide foster care and adoption assistance. ACF programs typically provide funds to states and communities to enable them to develop programs and supports to address social and economic issues related to poverty.

#### **KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES**

**Administration on Developmental Disabilities (ADD):** ADD's mission is to enhance opportunities for community living for people with developmental disabilities. State Councils on Developmental Disabilities have worked to increase the independence, productivity, inclusion and integration into the community of people with developmental disabilities through a variety of system change, capacity building and advocacy activities. The Protection and Advocacy (P&A) program has a significant role in enhancing the quality of life of people with developmental disabilities in every community. Each P&A is authorized to investigate incidents of abuse and neglect and follow up reports of incidents or investigate if there is probable cause to believe that such incidents have occurred.

**Head Start:** Head Start programs provide children with disabilities and their families with the full range of comprehensive services available to children and provide individualized services as called for in the Individual Education Program (IEP). Local arrangements that provide supports to children in Head Start classrooms often include special education teachers and/or therapists employed by the local school system. Head Start is also a leading source of inclusive placements for preschoolers with disabilities. At least 10 percent of Head Start enrollment slots must be made available for children with disabilities. Early Head Start programs provide opportunities for infants and toddlers with disabilities to receive child development services in the program's "natural environment" and are also key collaborators in community efforts to implement Part C of the Individuals with Disabilities Education Act (IDEA) Early Intervention. In the 1999-2000 program year over 115,000 children with disabilities were enrolled in local Head Start and Early Head Start programs.

**Child Care Bureau (CCB):** CCB funds child care programs for young and school age children and provides incentives and training programs to develop child care services and providers for children with special needs.

**Office of Family Assistance (OFA):** OFA administers the TANF program. Many families who remain on welfare face significant barriers to work, including disabilities, in particular, mental health problems, developmental disabilities, and learning disabilities. In addition, a significant number of welfare recipients have children with disabilities.

OFA has incorporated disability issues into its programs and guidelines and sponsors programs to assist and support TANF recipients with learning disabilities when they move to work. In carrying out these activities, OFA has collaborated with other federal agencies including the Department of Labor, the Department of Agriculture, Centers for Medicare & Medicaid Services, the Department of Housing and Urban Development, and the Department of Education (in particular, Adult and Vocational Education). OFA also has supported regional conferences, videoconferences, and training programs on welfare-to-work and persons with disabilities.

**Office of Community Services (OCS):** OCS works with Community Action Programs and Agencies, Community Service Block Grant (CSBG) state offices, and state agencies coordinating activities related to persons with disabilities and explores ways to involve Empowerment Zones and Enterprise Communities (EZ/EC) Program in activities related to Executive Order 13217.

OCS has undertaken numerous regional activities related to individuals with disabilities. Activities range from monitoring to improvements in home ownership, transportation, Head Start performance, family and community education, and other efforts aimed at integration and community access. Community integration is a specific goal of these activities, as is training communities to monitor the availability and quality of community services.

## **ADMINISTRATION ON AGING (AoA)**

### **AGENCY DESCRIPTION**

AoA supports a nationwide aging network, providing services to the elderly, especially services needed to enable them to remain independent. AoA supports some 240 million meals for the elderly each year, including home-delivered “meals on wheels,” helps provide transportation and at-home services, supports ombudsmen services for the elderly and provides leadership on aging issues.

AoA's statutory mandate under the Older Americans Act (OAA) is focused on helping older people remain independent in their homes and communities through the provision of supportive services and the development of coordinated systems of long-term care at the state and local level. The AoA currently administers over \$1 billion in OAA resources to support the development and operation of home and community-based care programs for

older individuals. Programs are carried out through a national infrastructure that consists of 56 state Units on Aging, 655 Area Agencies on Aging, 235 tribes and native organizations, and 29,000 local service providers.

The OAA and the Aging Network use a “bottom up” approach to planning and service delivery that is driven by the needs of local communities and older individuals. AoA’s Aging Network has played a leadership role in long-term care in many states, as evidenced by the fact that state Units on Aging have lead responsibility for managing Medicaid home and community-based waivers in 26 states.

## **KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES**

With the passage of the Older Americans Act Amendments of 2000, Congress established the National Family Caregiver Support Program to assist families caring for older persons who are ill or who have disabilities. Congress provided \$125 million for this new program in fiscal year 2001. In February 2001, HHS Secretary Thompson announced the release of \$113 million in grants to states to begin implementing this program.

AoA also administers the Alzheimer’s Disease Demonstration Grants to States Program (ADDGS), in which 25 states participate. AoA partners with the Centers for Medicare & Medicaid Services (CMS) to provide education and technical assistance to Indian tribes on home and community-based services options for Indian elders with disabilities.

## **AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)**

### **AGENCY DESCRIPTION**

AHRQ supports research designed to improve the outcomes and quality of health care, reduce its costs, address patient safety and medical errors, and broaden access to effective services. The research sponsored, conducted and disseminated by AHRQ provides information that helps people make better decisions about health care.

### **KEY PROGRAMS AND HOW THEY SERVE PERSONS WITH DISABILITIES**

The agency has long been involved in funding and conducting research around the delivery of health care services to individuals with disabilities. Recent activities are as follows:

The agency announced grant funding on July 31, 2001, for health services research centered around the questions of the interaction of the *Olmstead* decision with market forces and the financing and organization of health care delivered to individuals with disabilities.

In addition, the agency recently held an expert meeting on disability research where participants made suggestions as to where the agency should focus its research agenda.

These included, but were not limited to, research on barriers that impede the delivery of services for persons with disabilities; how to foster better transitions among care systems; and assistive technologies and rehabilitation services as they specifically apply to persons with disabilities. The information obtained during the meeting will help to inform the agency on new program opportunities.

In July, 2001, AHRQ held a national workshop entitled, "Beyond *Olmstead*: Making Community Based Services Work for All Persons with Disabilities." The workshop provided tools for consumers, providers, advocates, and state and local policymakers to assess consumer needs and planning for successful transactions from institutions and increasing the types and levels of support for persons already living in the community. Participants shared research in the area of community integration that will help inform AHRQ's research agenda.

## **OFFICE OF THE ASSISTANT SECRETARY FOR BUDGET, TECHNOLOGY AND FINANCE (ASBTF)**

### **AGENCY DESCRIPTION**

The Office of the Assistant Secretary for Budget, Technology, and Finance provides advice and guidance to the Secretary and other HHS senior officials on budget, financial management, and information technology matters, and coordinates these activities throughout the Department. As such, this office is a key agency in the formulation of programmatic and policy initiatives to improve access to community living for persons with disabilities who are eligible for Department programs and services, including oversight of compliance with the provisions of Section 508 of the Rehabilitation Act that require federal agencies to ensure that members of the public with disabilities who seek federal agency information or services have comparable access to and use of information and data as the public without disabilities, unless an undue burden would be imposed on the agency.

## **OFFICE OF THE ASSISTANT SECRETARY FOR PUBLIC AFFAIRS (ASPA)**

### **AGENCY DESCRIPTION**

ASPA provides valuable information on administration and HHS programs and initiatives such as New Freedom, that have a real impact on the lives of people with disabilities and other individuals interested in the issue of long-term care.

### **KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES**

*Information preparation, dissemination, and access:* ASPA disseminates information on HHS disability programs (updated regularly) that highlights the President's New Freedom Initiative while providing a comprehensive look at other HHS programs that serve people

with disabilities. ASPA also issues releases notifying the media and the public whenever new grants are announced to improve the availability of community-based services within the states. ASPA also works with ASBTF in ensuring that members of the public with disabilities who seek federal agency information or services have comparable access to and use of information and data as the public without disabilities, unless an undue burden would be imposed on the agency compliance, as required by provisions of Section 508 of the Rehabilitation Act.

## **OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION (ASPE)**

### **AGENCY DESCRIPTION**

The Office of Disability, Aging and Long-Term Care Policy within the Office of the Assistant Secretary for Planning and Evaluation is responsible for the development, coordination, research and evaluation of HHS policies and programs that support the independence, productivity, health, long-term care and economic security of children, working-age adults, and older persons with disabilities. The office is also responsible for policy coordination and research to promote the economic and social well-being of people with disabilities and the elderly.

### **KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES**

ASPE initiatives cover a broad range of issues:

*Cash and Counseling Demonstration and Evaluation: In-Home and Community-Based Services:* Funded by ASPE and the Robert Wood Johnson Foundation, this state-based demonstration tests whether a cash benefit enhances the ability of Medicaid-recipient elders and younger adults with disabilities to design personal assistance services that best meet their needs (while maintaining overall program budget neutrality). The concept behind this project is promotion of consumer direction and the enabling of consumer choice in the provision of personal and essential services as well as when and how they are provided. The initiative is based in three states (Arkansas, Florida and New Jersey) and assists older persons and children and non-elderly adults with disabilities.

*Home and Community-Based Services Resource Network:* Funded by ASPE and CMS, the Home and Community-Based Services Resource Network was established in September 1999 to bring the federal government, states, and person of all ages with disabilities together to expand access to high-quality, consumer directed services in a cost-effective manner. The Resource Network supports state efforts to engage in collaborative planning and policy development, and focuses on practical and immediate next steps to expand access to supportive services in ways that are realistic, equitable and affordable. The Resource Network is governed by a 12-member Project Board, equally comprised of representatives of state HCBS agencies

and consumers of HCBS services. Resource Network activities include web site information, technical assistance, conferences and other means of dissemination.

*Frontline Workers in Long-Term Care Technical Expert Panels:* Funded by ASPE's Division of Disability, Aging and Long Term Care Policy, and the Robert Wood Johnson Foundation, this project is designed to heighten awareness among federal, state, and local policymakers, long-term care providers, consumers, and foundations about shortage and training issues related to the frontline long-term care paraprofessional workforce, including people who work for nursing homes, home care agencies and non-medical residential facilities and people who work as independent providers. The project is designed to promote successful training, recruitment, and retention models for frontline workers, identify training needs; analyze policy options; identify data gaps; and develop a research and demonstration strategy that the government and foundations can undertake to improve policymaking.

## **CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)**

### **AGENCY DESCRIPTION**

The Centers for Disease Control and Prevention (CDC) is recognized as the lead federal agency for protecting the health and safety of people at home and abroad, providing credible information to enhance health decisions, and promoting health through strong partnerships. CDC serves as the national focus for developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve the health of the people of the United States. The CDC provides a system of health surveillance to monitor and prevent outbreak of diseases. With the assistance of states and other partners, CDC guards against international disease transmission, maintains national health statistics, provides for immunization services and supports research into disease and injury prevention.

### **KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES**

Numerous CDC activities relate to improving the health, well-being and participation of people with chronic illness and disability, including collaboration on national systems for disability and chronic illness measurement, strategic planning aimed at achieving disability-related objectives identified in Healthy People 2010, and working with states to develop disability programs as part of their overall public health activities. Currently 14 states have public health programs addressing the health of people with disabilities.

## CENTERS FOR MEDICARE & MEDICAID SERVICES (CMS)

### AGENCY DESCRIPTION

CMS administers the Medicare and Medicaid programs, which provide health care to aged and disabled workers, as well as to low-income populations. Together, Medicare and Medicaid insure approximately one out of every four Americans. CMS also administers the State Children's Health Insurance Program (SCHIP), which covers more than 2.2 million children.

### KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES

**Medicare:** Medicare is the nation's largest health program, covering 39 million Americans, 6 million of whom are either under 65 and disabled (5 million persons) or receive benefits because they have end-stage renal disease (ESRD) (1 million persons). Nearly 30 percent of all beneficiaries report fair to poor health. In 1999 Medicare spent \$5,410 per beneficiary. More than 75 percent of all spending is spent on the 15 percent of all beneficiaries who incur annual costs greater than \$10,000.

Medicare provides a broad range of medical services used by persons with chronic illness and disabilities. Medicare benefits are available through both the original program as well as through managed care organizations that participate in the Medicare+Choice program. Medicare+Choice contractors may furnish services that are not covered under the original Medicare program. CMS administers the program and sets broad standards for program operation and performance.

**Medicaid:** The Medicaid program is the third largest source of health coverage in the United States after employer-based coverage and Medicare. As the largest program in the federal "safety net" of public assistance programs, Medicaid provides essential medical and medically related services to the most vulnerable populations in society. The significance of Medicaid's role in providing health coverage cannot be overstated. Medicaid covered more than 40 million persons, 12.0 percent of the total U.S. population in 1998, compared to 9.1 percent in 1978.

The Medicaid program covers millions of low-income women, children, elderly people and individuals with disabilities. In general, Medicaid provides three types of critical health protection:

- (1) health coverage for low-income families with children and people with disabilities;
- (2) long-term care for older Americans and individuals with disabilities; and
- (3) supplemental coverage for low-income Medicare beneficiaries for services not covered by Medicare (e.g., outpatient prescription drugs) and Medicare premiums, deductibles and cost sharing.

Medicaid is a joint federal and state program. Each state establishes its own eligibility standards, benefits package, payment rates and program administration under broad federal guidelines. As a result, there are essentially 56 different Medicaid programs - one for each state, territory and the District of Columbia.

In general, Medicaid eligibility is based on a combination of financial and categorical eligibility requirements. Participating states must extend coverage to certain groups of individuals known as mandatory categorically needy persons. Included in this group are persons who receive SSI benefits. In addition, states have the option to cover other eligibility groups, many of which are designed to reach children and adults with disabilities. Key examples of these disability-related optional groups are recipients of SSI supplements, low-income persons in need of long-term care (both institutional and community-based services), workers with disabilities and serious impairments. CMS initiatives to promote community integration frequently involve these optional groups.

Medicaid benefits range over primary, acute and long-term institutional and community services. In this regard, the Medicaid benefit package is defined by each state based on broad federal guidelines. Cost sharing, when permitted at all, is nominal. There is much variation among state Medicaid programs regarding not only which services are covered, but also the amount of care provided within specific service categories (i.e., amount, duration, and scope of services). Each state Medicaid program must cover "mandatory services" identified in statute. In addition to covering the mandated services, states have the discretion to cover additional services - i.e., "optional services." States may choose among a total of 33 optional services to include in their Medicaid programs.

At their option, states may seek to furnish "home and community-based care services" through special waivers. State waiver programs may specify the beneficiary sub-groups eligible for services, the classes and amount of services covered, and may establish upper limits on the number of individuals who may receive home and community services.

States have the option to mandate enrollment of certain beneficiaries in some form of managed care arrangement as a condition of coverage and may also offer managed care on an optional basis. It has been estimated that in 1999 approximately 25 percent of all Medicaid managed care enrollees had some form of disability.

Medicaid is financed through a combination of state expenditures and federal financial payments. In fiscal year 1998, program expenditures totaled \$175 billion with enrollment at 41.4 million people. Beneficiaries accessing services totaled 40.6 million, including: 18.9 million children, 7.9 million adults, 3.9 million elderly persons, and 6.6 million individuals who were blind or disabled. In fiscal year 2000, Medicaid expenses increased to \$195 billion.

**SCHIP:** The State Children's Health Insurance Program (SCHIP) enables states to obtain health care coverage for children from working families with incomes too high to qualify for Medicaid but too low to afford private health insurance through separate state programs, Medicaid expansions, or a combination of both. Each state with an approved plan receives



enhanced federal matching payments for its SCHIP expenditures up to a fixed state "allotment." As of July 1, 2000, 50 states, the District of Columbia and five U.S. territories have implemented SCHIP, covering over 2 million children. In addition, the number of children enrolled in Medicaid has increased because of state-wide outreach and eligibility simplification efforts. Of these approved plans, 15 states have created a separate child health program, 23 states have expanded Medicaid, and 18 states have developed a combination of a separate state program and a Medicaid expansion program. In addition, many states have already amended their programs to expand eligibility beyond their original proposal. Prior to SCHIP's creation, only four states covered children with family incomes up to at least 200 percent of the federal poverty level (about \$33,000 for a family of four). As of the summer of 2000, 30 states had plans approved to cover children with incomes up to at least this level. States have made strong progress in implementing their SCHIP programs, seeking and implementing new and innovative ways to identify and enroll uninsured children in both Medicaid and SCHIP. The steady growth of the SCHIP program is evidence of the success of this federal-state partnership and the nation's commitment to ensuring that all children have health insurance coverage.

States have broad flexibility in establishing coverage for children and may apply premium and cost sharing requirements. Certain benefits must be covered without charge, including immunizations and well baby and well child care. States may condition SCHIP coverage on enrollment in managed care.

## **FOOD AND DRUG ADMINISTRATION (FDA)**

### **AGENCY DESCRIPTION**

The Food and Drug Administration is one of the nation's oldest and most respected consumer protection agencies. In fact, FDA-regulated products account for about 25 cents of every consumer dollar spent in the United States. FDA's mission is to promote and protect the public health by, among other things, promptly and efficiently reviewing clinical research and taking appropriate action on the marketing applications of regulated products by ensuring that foods are safe, wholesome, sanitary, and properly labeled; human and veterinary drugs are safe and effective; there is reasonable assurance of the safety and effectiveness of devices intended for human use; cosmetics are safe and properly labeled; and public health and safety are protected from electronic product radiation. The FDA participates through appropriate processes with representatives of other countries to reduce the burden of regulation, harmonize regulatory requirements, and achieve appropriate reciprocal arrangements. The FDA consults closely with experts in science, medicine, and public health, and works with consumers and manufacturers as it carries out its regulatory responsibilities.

### **KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES**

FDA activities relate to improving the health, well-being and participation of people with chronic illness and disability, including strategic planning aimed at achieving disability-

related objectives identified in Healthy People 2010, providing consumers an opportunity to give the agency input during advisory committee meetings and other public meetings, and establishing in collaboration with others, guidelines to address the needs of older persons and persons with disabilities when developing standards. The FDA has just completed an extensive inventory of its outreach, recruitment and retention programs as they related to serving individuals with disabilities. This resulted in a 19-page document titled, "The FDA Plan for Employment of People with Disabilities in the Federal Government, February 2001."

## **HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)**

### **AGENCY DESCRIPTION**

HRSA helps provide health resources for medically underserved populations. HRSA supports a nationwide network of community and migrant health centers and primary care programs for the homeless and residents of public housing, serving 11.5 million persons at 3,400 sites. HRSA also works to build the health care workforce and maintains the National Health Service Corps, oversees the nation's organ transplantation system, works to decrease infant mortality and improve child health, and provides services to people with AIDS through the Ryan White CARE Act Programs.

The mission of HRSA is to improve the nation's health by assuring access to comprehensive, culturally competent, quality health care for all. HRSA serves as a national resource in not only assuring the availability of quality health care to underserved, vulnerable and special needs populations, but also in meeting the unique health care needs of these groups. HRSA programs target the uninsured, inner city and rural residents of underserved communities, a half million persons receiving aid services under the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and persons who require organ transplants.

HRSA emphasizes the delivery of primary health care at the community level. Consequently, most of HRSA's programs are supportive of the New Freedom Initiative's goal of providing qualified individuals with disabilities of all ages with services in community settings whenever appropriate. Primary grantees include state and local governmental entities and community-based nonprofit organizations.

### **KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES**

**Maternal and Child Health:** A key goal as part of the overall administration of the Title V block grant, is to ensure that a system of community-based services is in place for children with special needs, to set specific outcomes goals for children with special needs, and to remove the barriers associated with each outcome area. The ultimate goal is a successful transition to all aspects of adulthood, including adult health care, employment and independent living. The plan that will be developed to support this initiative will be disseminated to the agency's partners including families and youth with special health care needs; health care professionals across disciplines; public and private insurance; academia;

foundations and non-profit organizations; employers; vocational rehabilitation providers; and federal, state and local government.

**HIV/AIDS:** HRSA supports the development of clinical, medical, and wrap-around support services to assure persons the greatest level of self-reliance and self-determination. The CARE Act supports the integration of care through the support of case management services. In fiscal year 2000, about 43 percent of CARE Act funds allocated were for health care services including mental health and substance use, 27 percent were for support services and almost 12 percent were for case management services.

**Community Health Centers:** Health centers are a central part of the health care safety net for the nation's indigent populations, providing family-oriented access to comprehensive primary and preventive health care in community settings, regardless of ability to pay. In 2002, health centers will treat 11.5 million patients at more than 3,400 sites. In addition to delivering health care services, many centers also provide enabling services, such as transportation, case management, outreach, housing referrals, entitlement program eligibility assistance and other services that enhance patients' ability to fully utilize needed services. The Health Care for the Homeless Program, for example, provides services specifically aimed at homeless individuals with a disability due to mental illness. These community-based services are often linked with substance abuse treatment services because individuals are often dually diagnosed with a mental illness and a substance abuse problem.

In response to an identified need in the 1980s, a handbook for primary care providers delivering services to people with disabilities was prepared and distributed to certain Community and Migrant Health Center clinicians. The Bureau of Primary Health Care plans to update the Handbook for Primary Care Providers to focus on treating people with physical disabilities and sensory impairments, with an emphasis on the efficient and sensitive delivery of primary care services to people with disabilities. The initial version of the handbook covered treating persons with chronic disease-related disabilities, infectious disease-related disabilities, and alcohol/substance abuse-related disabilities.

**Office of Rural Health:** The Office of Rural Health Policy administers two grant programs that support collaborative models to deliver basic health care services to the 70 million Americans living in rural areas. The Rural Health Outreach grant program increases access to primary health care services for rural Americans in their own communities. The program supports a wide range of services, including primary medical and dental care, mental health treatment, health promotion and health education services, and hospice care.

The Rural Network Development grant program helps rural providers develop community-based, integrated systems of care. Projects build regional or local partnerships among local hospitals, physician groups, long-term care facilities, and public health agencies to improve management of scarce health resources. Both programs require extensive collaboration among program participants and are restricted to rural-based organizations.

**Telehealth Program:** Telehealth projects provide support for a wide array of activities to improve quality health services for persons in isolated areas as well as support of health care practitioners. Rural telemedicine projects in a five-region area of Oklahoma and rural California bring specialty care and patient supports to children and adults with disabilities living in remote rural areas.

**National Health Service Corps (NHSC):** The NHSC supports the deployment of qualified, culturally competent health care professionals in rural and urban communities experiencing health professions shortages. More than 2,500 clinicians provide primary health care in communities that have a shortage of health professionals in exchange for scholarships and loan repayment through the NHSC.

**Center for Health Services Financing and Managed Care:** The center will be working to assure access to comprehensive and quality care for Medicaid beneficiaries with disabilities. Many Medicaid agencies have required Medicaid beneficiaries with disabilities to enroll in managed care arrangements, including enrollment in Managed Care Organizations (MCOs). This has resulted in MCOs accepting financial risk for providing services to beneficiaries with disabilities. Many MCOs previously have not been financially responsible for providing comprehensive health services for people with disabilities. The center will be sponsoring a series of technical assistance workshops for states, MCOs, and HRSA-funded providers. Workshops will focus on techniques to assure services are provided within Medicaid capitated rates or to pursue approaches to rate adjustment and ensure the continuity and quality of care in an effort to provide services in the most integrated community setting.

**Division of Vaccine Injury Compensation:** Through the National Vaccine Injury Compensation Program (VICP), the Division of Vaccine Injury Compensation promotes the ability of individuals with disabilities to live in home and community-based settings through its streamlined system of providing individualized compensation packages for those with vaccine-related injuries. The National Childhood Vaccine Injury Act of 1986, which created the VICP, not only provides compensation to persons injured by vaccine but also supports the coverage of unreimbursable medical expenses and the development of life care plans.

## **INDIAN HEALTH SERVICE (IHS)**

### **AGENCY DESCRIPTION**

The Indian Health Service (IHS) directly provides health care services for approximately 1.5 million American Indians and Alaska Natives (AI/AN) from more than 550 Tribes. IHS supports a network of 37 hospitals, 60 health centers, three school health centers, 46 health stations, and four urban Indian health centers to provide services to nearly 1.5 million American Indians and Alaska Natives of 557 federally recognized Tribes. Additionally, there are 34 urban Indian health organizations operating at 41 sites in cities located across the United States. About one third of IHS programs are carried out by Indian tribes and tribal organizations under the Indian Self-Determination Act.

## **KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES**

The potential for long-term significant disability for AI/ANs is evident. Tribal leaders cite diabetes, alcoholism and substance abuse, and unintentional injuries as rising to crisis proportions in their communities. Additionally, health care providers and community health representatives report significant health problems including tuberculosis, mental health problems, and other health concerns in many AI/AN communities. A report prepared in 2000 by the Native American Committee of the Presidential Task Force on Employment of Adults with Disabilities indicates that more than 26 percent of the AI/AN population, nearly a half a million people, lives with a significant disability. Many others experience the effects of less significant disabilities or disabilities that are *hidden*, including many forms of mental illness, alcohol and substance abuse, asthma, and early stages of diabetes.

To address these issues, the IHS has taken numerous steps, including launching a three-year demonstration project for AI/AN elders and people with disabilities in collaboration with CMS. The demonstration project's purpose is to identify eligible individuals for Medicare, Medicaid and disability programs and ensure the receipt of benefits. IHS engages in research activities, disability prevention efforts, and efforts to promote employment of adults with disabilities. IHS has developed partnerships with SAMHSA to fund comprehensive community-based services for children and families that experience mental illness, developmental disabilities or delays substance abuse and other risks. IHS also is involved in a Mental Health and Community Safety Initiative, in collaboration with other federal agencies both within and outside of HHS, that addresses children's mental health, substance abuse, and violence issues in AI/AN communities.

## **INTERGOVERNMENTAL AFFAIRS (IGA)**

### **AGENCY DESCRIPTION**

The mission of Intergovernmental Affairs is to facilitate communication regarding HHS initiatives as they relate to state, local, and tribal governments. IGA is the departmental liaison to state governments and serves the dual role of representing the state and tribal perspective in the federal policymaking process as well as clarifying the federal perspective to state and tribal representatives. IGA plays a key role in the development and implementation of policies and program initiatives to reduce and eliminate barriers to community living for persons with disabilities.

## **NATIONAL INSTITUTES OF HEALTH (NIH)**

### **AGENCY DESCRIPTION**

Comprised of 27 separate institutes and centers, the National Institutes of Health (NIH) is the world's premier medical research organization, supporting some 35,000 research projects nationwide in a range of diseases and conditions. The mission of the NIH is to uncover new knowledge that will lead to better health for everyone. NIH carries out

activities and programs through its organizational units, the Institutes and Centers (ICs).

## **KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES**

Numerous Institutes within NIH are involved in research related to health care for persons with disabilities. The following description of major projects highlight activities across the agency:

- The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Intramural Research Program launched the Health Partnership Program to reduce health disparities in diseases of the joints, muscles, bones, and skin among minority communities.
- NIH supports major efforts to improve craniofacial, oral and dental health through research conducted through the National Institute of Dental and Craniofacial Research (NIDCR), which has become a leader in the field of pain research;
- The National Institute of Neurological Disorders and Stroke (NINDS) has undertaken research initiatives to reduce the incidence of stroke and Parkinsons Disease as well as other neurological disorders that affect hundreds of thousands of persons annually. A key element of this initiative involves the testing of a transitional care model that uses a multidisciplinary team and involves comprehensive discharge planning, including determination of patient care needs outside the hospital, and follow-up in the home by advanced practice nurses specializing in geriatrics.
- The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Nursing Research (NINR) both conduct and support research on diabetes, with an emphasis on therapies that allow maximum daily functioning levels among children, new environmental approaches to obesity prevention, and prevention efforts aimed at type 2 diabetes in children and adolescents.
- National Center for Complementary and Alternative Medicine (NCCAM) grantees are testing the value and the mechanisms of acupuncture for pain relief and are exploring alternative forms of treatment for osteoarthritis and coronary artery disease.
- Depression is a major focus of the National Institute for Mental Health (NIMH) not only because of its direct effects but because of its link to physical health. In addition, NIMH is allocating new funds for research that can capitalize on the fruits of the genome project because of its relevance to mental illness. Of particular emphasis is research in the areas of schizophrenia, bipolar disorder, autism, early-onset major depression and other disorders.
- The National Cancer Institute (NCI) has identified a software system that will allow any desktop PC to become a "text telephone" and communicate "person-to-person" with TTYs used by the deaf and hard-of-hearing community.
- The National Institute on Deafness and Other Communication Disorders (NIDCD) also supports the development of assistive technologies for those who are deaf or hard-of-hearing or have voice, speech or language disabilities and loss of balance, smell or taste. For example, NIDCD supports and conducts research and research training in

the normal processes and the disorders of human communication that affect approximately 46 million Americans.

- The National Institute of Child Health and Human Development (NICHD) program in human learning and learning disabilities develops and supports research initiatives to increase knowledge relevant to normal and atypical development of reading, written language and mathematics abilities throughout the lifespan. This program emphasizes the development of prevention, early intervention, remediation and classroom instructional approaches and methods to ensure robust acquisition of reading, written language and mathematics skills at different stages of development. During the past five years, converging evidence derived from the NICHD reading research network has led to the development of early screening measures that can identify, with over 85 percent accuracy, kindergarten children who are at risk for reading failure. In turn, early intervention and reading remediation trials at 11 sites within the network have developed treatment and instructional approaches that help all but 5 to 7 percent of children attain average or above reading skills.
- The National Center for Medical Rehabilitation Research (NCMRR) explores a wide range of approaches to promote recovery and enhance function in persons with neurologically incomplete spinal cord injury, improvements in wheelchair function and durability, and improvements aimed at assisting individuals with loss of limbs.
- In the area of cardiovascular diseases, the National Heart, Lung, and Blood Institute (NHLBI) is focusing particular attention on subgroups of the population who are at high risk. The landmark Jackson Heart Study, now well under way, was established to investigate the causes of the disproportionate burden of cardiovascular disease borne by African-Americans in the United States and to uncover better preventive approaches.
- The National Eye Institute (NEI) aims to increase awareness of low vision and its impact on quality of life and is directed toward people with low vision, their families and friends, and health care and service professionals who care for them. The National Eye Institute (NEI) supports research to understand the origins of visual impairment and assist in the rehabilitation of those who have such disabilities.
- The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) targets resources on research into many diseases and conditions that can compromise the quality of life for older people. Osteoporosis, a skeletal disorder characterized by compromised bone strength, is one of the seven most common causes of disability in older people, especially older women. One out of every two women (as opposed to one in eight men) over 50 will have an osteoporosis-related fracture in her lifetime.
- The National Cancer Institute (NCI) has just completed an extensive inventory of its outreach, recruitment and retention programs as they relate to serving individuals with disabilities. This inventory resulted in a 16-page implementation program for NIH's Disability Plan, titled "Accessing Opportunity: The Plan for Employment of People with Disabilities in the Federal Government."

## OFFICE FOR CIVIL RIGHTS (OCR)

### AGENCY DESCRIPTION

The Office for Civil Rights (OCR) ensures that individuals have equal access to and the opportunity to participate in programs and services funded or provided by HHS without being subjected to unlawful discrimination. OCR activities include investigation of complaints, reviews of compliance with federal legal requirements, voluntary dispute resolution, technical assistance and policy development. Through preventing and eliminating unlawful discrimination, OCR helps HHS carry out its overall mission of improving the health and well-being of individuals affected by HHS programs.

### KEY PROGRAMS AND HOW THEY SERVE INDIVIDUALS WITH DISABILITIES

Among the civil rights laws enforced by OCR is Title II of the Americans with Disabilities Act (ADA), which prohibits discrimination on the basis of disability by state and local governmental entities, and Section 504 of the Rehabilitation Act of 1973, which prohibits disability-based discrimination by the recipients of federal financial assistance and by federally conducted programs. OCR is working to resolve more than 300 complaints filed with OCR by complainants in approximately 36 states who allege violations of the ADA Title II “integration regulation.” As the Supreme Court ruled in *Olmstead v L.C.*, the ADA and the integration regulation require that qualified individuals with disabilities must be provided with services in the most integrated setting when: (a) treatment professionals reasonably determine that such placement is appropriate; (b) the affected persons do not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving state-supported disability services. OCR is also promoting compliance with Title II of the ADA and Section 504 by working with states to voluntarily resolve *Olmstead* complaints and to engage in planning to serve the needs of individuals with disabilities for community-based care. In *Olmstead*, the Supreme Court suggested that states may be able to demonstrate compliance with Title II by adopting a “comprehensive, effectively working plan” to serve individuals with disabilities in the most integrated setting. OCR staff in 10 regions nationwide are aiding approximately 40 states in undertaking broad-based *Olmstead* planning efforts. In addition, in a few states, OCR has served as a mediator working to resolve private litigation between states and litigants who allege violations of Title II of the ADA.

OCR is working with expert consultants to provide on-site technical assistance to states engaged in collaborative planning efforts. With the help of these experts, OCR is developing technical assistance products to help guide states in their efforts and has conducted a specific technical assistance conference call on housing.

OCR’s leadership in the New Freedom Initiative Group, and in other collaborative efforts among HHS components, has led to policy initiatives and program changes to enhance the ability of states to improve access to home and community-based services and comply with the ADA.



OCR has worked with CMS to issue five “state Medicaid director” letters (some jointly) to address *Olmstead* implementation and compliance issues. The letters include policy clarifications and changes to enhance states’ flexibility to create and implement home and community-based waivers and provide guidance to states regarding the *Olmstead* decision and its impact on programs.

OCR worked closely with CMS to develop criteria for awarding more than \$70 million in new grant funds states to aid community integration, including 1) \$50 million in "Real Choice Systems Change Grants," designed to help states improve health and long-term care systems for seniors and people with disabilities; 2) \$15 million in grants, along with Section 8 housing vouchers, to help all people with disabilities move from institutions to community-based settings; and 3) \$8 million to enhance community-based personal assistance services to ensure maximum control by people with disabilities of all ages.

OCR is working with other federal agencies, including HUD and DOJ, to foster collaborations and promote consistency within the federal government regarding Title II compliance issues. OCR has collaborated with HUD identify ways in which affordable, accessible housing can be made more readily available to individuals with disabilities. Most recently, OCR and other HHS components collaborated with HUD to present a nationwide *Olmstead* technical assistance teleconference on “Understanding HUD Section 8 vouchers.”

## **OFFICE OF INSPECTOR GENERAL (OIG)**

### **AGENCY DESCRIPTION**

The OIG performs audits and investigations and conducts research to ensure the integrity of federal programs and expenditures. The activities of the OIG are aimed at protecting federal programs that furnish health and human services to all persons, including persons with disabilities.

### **KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES**

OIG’s extensive body of investigation and civil and criminal enforcement work frequently focuses on issues of major importance to persons with disabilities.

Many OIG reports focus on issues of particular concern to persons with disabilities and are aimed at identifying barriers and solutions to achieving community integration. Examples are reviews of Medicaid managed behavioral health care programs for children, inspection reports focusing on younger adults with mental illness who reside in nursing homes and the issue of “most integrated care” settings, the care of persons with mental retardation and developmental disabilities, and assessments of state systems to identify abuse and neglect of persons with disabilities (up to 90 percent of whom reside in facilities, such as group homes, residential schools, and supervised apartments, that do not receive Medicare or Medicaid funding).

Additional OIG reports address residential habilitation services for individuals with mental retardation and developmental disabilities, false claims by residential facilities caring for persons with mental retardation and developmental disabilities, and related matters.

The agency also has engaged in extensive Medicare investigative work in the areas of inpatient and outpatient psychiatric services, Medicare carrier policies in the area of mental health services, the use of restraints and seclusion, psychotropic drug use in nursing homes, and other related matters.

## **OFFICE OF PUBLIC HEALTH AND SCIENCE (OPHS)**

### **AGENCY DESCRIPTION**

The Office of Public Health and Science (OPHS) serves as the focal point for leadership and coordination across the Department in public health and science; provides direction to program offices within OPHS; and provides the Secretary of HHS with advice and counsel on public health and science issues. Among the OPHS offices whose work is relevant to the New Freedom Initiative and the implementation of Executive Order 13217 are the Office of the Surgeon General, the Office of Minority Health and the Office on Women's Health.

### **KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES**

**The Office of the Surgeon General** engages in a wide variety of activities to protect and advance the health of the Nation. The work of the Office of the Surgeon General includes educating the public, advocating for effective disease prevention and health promotion programs and activities and providing a highly recognized symbol of national commitment to protecting and improving the public's health. The Surgeon General articulates scientifically based health policy analysis and advice to the President and the Secretary of HHS on the full range of critical public health, medical, and health system issues facing the Nation. The Surgeon General provides leadership in promoting special Departmental health initiatives, including initiatives concerning individuals with disabilities. For example, in June 2001, HHS launched a Surgeon General's Initiative on Health Disparities and Mental Retardation to identify critical challenges and to develop a national action plan to promote the health of individuals with mental retardation and to enable them to live, go to school and work in their communities. In recent years, the Surgeon General has issued well-regarded reports on issues affecting individuals with disabilities, including a 1999 report on mental health and a 2001 report focusing on culture, race and ethnicity in mental health.

**The Office of Minority Health (OMH)** is dedicated to the mission of improving the health of racial and ethnic populations throughout the development of effective health policies and programs to help eliminate disparities in health. OMH works closely with sister agencies within HHS and their minority health representatives, has a role in the development and coordination of federal health policy and works to improve collection and analyses of data

on the health of racial and ethnic populations. OMH also monitors efforts to achieve the goals of “Healthy People 2010,” which has a special focus on eliminating racial and ethnic disparities in health. OMH cooperative agreements and grants help launch research and demonstration projects. OMH administers grant programs in an effort to facilitate community linkages and strategies that use scarce resources efficiently and across organizational lines. OMH is expanding its activities relating to HIV/AIDS. OMH has established the Office of Minority Health Resource Center to meet the public’s need for reliable, accurate and timely information and technical assistance on issues affecting the health of minority populations.

**The Office on Women’s Health (OWH)** is the government’s champion and focal point for women’s health issues. OWH works to promote women’s health through coordinating HHS women’s health initiatives; engaging in public/private partnerships; engaging in health promotion and outreach; promoting the development and implementation of model initiatives to address the health needs of women across ages, cultures and races and ethnicities; promoting comprehensive and culturally appropriate prevention, diagnostic and treatment services for women across the lifespan; promoting the efforts of the Surgeon General’s Initiative to Eliminate Racial and Ethnic Disparities in Health status; stimulating the development and implementation of effective women’s health policies; and supporting regional women’s health coordinators in each of HHS’ 10 regional offices throughout the country. OWH is also involved in efforts to focus attention on issues concerning the health of older women, including older women of color.

## **PROGRAM SUPPORT CENTER (PSC)**

### **AGENCY DESCRIPTION**

The Program Support Center does not operate programs that directly impact on community services for individuals with disabilities. Rather, its human resource service component provides recruitment services on a “service-for-fee” basis for individuals with disabilities for positions in PSC, HHS and other customer agencies throughout the federal government.

## **SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)**

### **AGENCY DESCRIPTION**

SAMHSA is the lead federal agency with responsibility for assuring the availability and accessibility of comprehensive systems of care and direct services for individuals with substance abuse and/or mental disorders. Among other priorities for the agency is a focus on integrating services to create comprehensive systems of care for individuals with mental illness or with co-occurring substance abuse and mental disorders.

## KEY PROGRAMS AND HOW THEY SERVE PEOPLE WITH DISABILITIES

SAMHSA serves as the umbrella under which substance abuse and mental health service centers are housed, including: the Center for Mental Health Services (CMHS), the Center for Substance Abuse Prevention (CSAP), and the Center for Substance Abuse Treatment (CSAT). SAMHSA also houses the Office of the Administrator, the Office of Applied Studies and the Office of Program Services. SAMHSA and its centers' programs are improving the quality and availability of substance abuse prevention, addiction treatment and mental health services nationwide.

SAMHSA and its centers have extensive experience in integration of services, collaboration between multiple funding streams and service delivery systems, as well as interdepartmental and interagency collaboration to meet the complex needs of people with serious mental illnesses and people with co-occurring substance abuse and mental disorders. Much of SAMHSA's current activity in this area builds on the success of earlier SAMHSA programs. One example of such program is the Community Support Program (CSP). Created in 1977, CSP is a model that is based on an integrated, comprehensive system of care including mental health, social services, rehabilitation, housing, employment, physical health, income support, substance abuse, peer support, and other needed services and supports to help the person reside in the community and prevent unnecessary institutionalization.

*Strategic Planning:* SAMHSA engages in strategic planning to achieve the aims of the *Olmstead* decision. Particular areas of emphasis are persons with substance abuse disorders, persons with mental illness who are homeless, aging adults with mental illness, and persons with co-occurring disorders.

*Services:* SAMHSA's centers are the locus of activity for the statutory mental health and substance abuse block grant programs, which constitute approximately 70 percent of the agency's budget. These large grants are complemented by an array of other formula grant programs (Protection and Advocacy, and Projects for Assistance in Transition from Homelessness) and Targeted Capacity Expansion (TCE) programs that provide services support to address emerging and unmet needs. SAMHSA's federal block and formula grant funding enables states to maintain and enhance substance abuse and mental health services and systems.

SAMHSA supports a wide range of technical assistance and information dissemination activities to support capacity enhancement and development. The following examples illustrate agency technical assistance initiatives:

1. A National Dialogue on Co-Occurring Mental Disorders and Substance Abuse involving multiple state agencies that has resulted in a framework for the development of integrated service systems.

2. Policy guidance on the use of Substance Abuse Prevention and Treatment Block Grant funds and Community Mental Health Services Block Grant funds in conjunction with each other to provide services to people with co-occurring disorders, as well as key principals in the delivery of integrated treatment for people with co-occurring disorders, and areas where additional research is needed.
3. Technical assistance under the Community Mental Health Services Performance Partnership Block Grant (CMHSBG) in order to develop community-based systems of care for children with serious emotional disturbance, adults with serious mental illness and aging adults.
4. Coalition building around community-based care, the dissemination of best practices information, and assistance aimed at community integration of persons with mental illness.
5. Management training seminars for senior-level executives in state mental health authorities, leadership training and technical assistance to State Mental Health Planning Councils, and an annual National Technical Assistance Mental Health Block Grant Conference on Community Mental Health Planning that permits state planners and mental health planning council members to share up-to-date information on the public mental health system and services integration.
6. Protection and Advocacy (P&A) grantees activities, located in the 59 states and territories, which pursue administrative, legal, and other appropriate remedies to investigate reports of abuse and neglect in public or private mental health inpatient and residential facilities and protect and advocate for the rights of individuals receiving mental health services. P&A staff work with the National Association of Protection and Advocacy Services (NAPAS) to ensure state P&As maintain leadership in monitoring consistency of the ADA integration mandate and delivery of long-term care. Training and technical assistance on community integration is provided to P&A advocates and attorneys.
7. Projects aimed at improving services to persons with serious mental illnesses, including those with co-occurring substance abuse disorders who are homeless or at risk of homelessness.
8. A "Building Mentally Healthy Communities" program that is intended to increase the capacity of local entities to provide prevention and treatment services to meet emerging and urgent mental health needs of communities. Grants are made to cities, counties and tribal governments to partner with community-based organizations to help them build the service system infrastructure necessary to address serious local or regional problems.
9. Technical support through the Substance Abuse Prevention and Treatment Performance Partnership Block Grant (SAPTBG), which supports community-

based and integrated treatment and prevention services through over 9,000 treatment and prevention providers nationwide. Assistance emphasizes a community's ability to provide a comprehensive, integrated, creative and community-based response for a targeted, well documented substance abuse treatment capacity problem. A number of the TCE grant projects specifically address treatment capacity for people with co-occurring substance abuse and mental disorders as well as persons with co-occurring cognitive and physical disabilities.

*Research to practice:* SAMHSA also emphasizes efforts to translate research to practice through programs that bridge the gap between knowledge and practice, including the translation of newly developed knowledge on best service practices from development to broad field application, technical assistance, education supports, tool kits, and other materials. Information about service needs obtained through the State Block Grant plans and TCE programs is fed back to the agency's research and knowledge development center divisions. The knowledge development and application (KDA) programs (discretionary grants) improve services by developing and evaluating new ways to organize, finance and deliver prevention and treatment services in communities through best practices. Key areas in which research to practice initiatives are under way are mental health and substance abuse, and activities focused on specific issues and target populations such as children and families, persons with co-occurring disorders, issues related to employment and rehabilitation, homelessness and aging adults.

SAMHSA is also taking steps to improve the quality and availability of state data. These efforts are being carried out through its Community Mental Health Services Block Grant, which represent a new paradigm in federal and state relations and cooperation Performance Partnerships. CMHS's 16-state Indicator Pilot Grant Program was funded from fiscal year 1998 to fiscal year 2001 to pilot 32 performance indicators. The final report will include data reports, instrument development, and definitional and piloting developments for the 16 state mental health agency grantees. This pilot provides a model for relevant and comparable reporting across states. Common themes are state comparability and assessment of changes across time. Examples of data products include three indicators: 1) consumer survey results from 10 states in the areas of access, appropriateness, outcome, and participation in treatment planning; 2) penetration and utilization rates for grantee states for 1998 - 2000 including age and gender comparisons; and 3) patient readmissions to state hospitals within 30 and 180 days by age, gender, and race/ethnicity by state.

SAMHSA also engages in extensive consumer empowerment-related activities through both policy and practice-related activities such as information dissemination, efforts to reduce stigma, inclusion of consumers on key national councils, and technical assistance projects aimed at empowering consumers.