

has resulted in improved health status, decreased hospitalization, a decrease in the unemployment rate, and decreased costs of care. The impact of this program has been dramatic. For example, between 1975 and 1985:

- The number of patients receiving comprehensive care and the number receiving care at home increased nearly five times
- The average number of hospital days per year per patient has been reduced by 80 percent
- The number of days lost from work or school each year has been reduced by 73 percent
- The percent of unemployed adults dropped from 36 percent to 9 percent
- The average cost of health care per year has been reduced from \$31,600 to \$8,100. This \$23,500 savings per patient represents an annual national savings of \$223 million.

EXAMPLE: Technology Assisted Children

State Title V Programs for Children with Special Health Care Needs in Illinois, Louisiana, and Maryland received grants from the Division of Maternal and Child Health to develop systems of regional care for technology assisted children. The results have been impressive, both in terms of quality care and cost savings.

These projects focus on the transfer of children from institutional settings to home or homelike settings through the use of teams of many different professionals. These projects have proven that family-centered, community-based systems can be developed through proper management and coordination.

In order to institutionalize cost-saving measures, the Illinois project staff identified important gaps in the health care delivery systems involved

in pediatric care at home; the Louisiana project emphasized coordinated management of hospitalization, to reduce the lengths of stay as well as costs; and the Maryland project established a Center for Coordinated Home and Community Care, a private non-profit organization, to facilitate hospital discharge and case management of special services in the community.

A report, *Alternatives to Hospitalization for Technology Dependent Children*, prepared by the National Maternal and Child Health Resource Center at the University of Iowa under a grant, *Future Directions of Services for Children with Special Health Care Needs*, concluded that the care of technology dependent children in a home setting is generally less costly to public and private third-party payers than long-term care in a hospital or institutional setting. However, data about the relative costs of home care and hospital or institutional care are not readily available, and additional research is needed to establish the relative costs of such care.

EXAMPLE: Other Conditions

Comprehensive programs in Pediatric Rheumatology, developed with Title V support, demonstrated that coordinated care can improve health status, decrease hospitalizations, improve school attendance, and control costs. Texas Children's Hospital has reduced hospitalizations by 50 percent using case management support teams. The Cincinnati Regional Center has improved school attendance above the norm for the local area (2/3 completed more than high school).

In children with diabetes, patient education has been demonstrated to improve patient health, lessen disease-related absenteeism, improve short-term control, and lessen the use of expensive health facilities. The key to cost-effective diabetes control is patient adherence to the diabetes regimen. Studies show that the regular health provider/patient contact in the community-based, coordinated care model substantially increases adherence to the regimen.

For the child with mental retardation the cost of institutional care is about four times the cost of care at home.

ACTION STEP 6**Encourage and Support
the Development of
Adequate Health Care Financing**

All children and their families should have access to adequate health insurance. A substantial number of Americans have no private or public health insurance for either all or part of the year, and the number is growing. In the under 65 population, children under 18 constitute a large proportion of the uninsured population. Even when insured, many families face high out-of-pocket expenses for many health care services which are not covered by their benefit packages.

While some services used by children with special health care needs are well covered, such as those provided in the hospital setting, community-based services are less well covered, including physician and nursing services, social work and nutrition services, physical therapy, respite care and family counseling. There have been some recent improvements in coverage of community-based services, especially care at home, after recognition of cost savings. While there are many potential sources of health care financing, they are often fragmented and confusing to parents.

Inadequate insurance, limitations on benefits, deductibles, co-payments, lack of coverage of certain types of services, and limits on maximum lifetime benefits all place significant hardships on families caring for children with special health care needs. We must work together to assure adequate financing to protect these children and their families.

- Health care insurance must be available for all children with special health care needs and their families.

- Health care insurance must adequately cover chronic care and care in the community; must recognize the comprehensive needs of children and their families, including supportive services; must not interfere with a family's employment options; must assure equal access to care for all children across geographic boundaries; and must protect the dignity and integrity of families.
- We must recognize the need for public funds which assist in developing the service systems of care. This could include case management and enhanced community services, as well as monitoring and standards development. One source of these funds is Title V.
- The methods of financing health care for children with special health care needs is an unsettled issue. Many different options are being considered to improve public and private insurance. Some of these options include expanding Medicaid coverage at the State level, Medicaid waivers, State risk pools to subsidize insurance for those whose medical condition makes it prohibitively expensive or impossible to get insurance, affordable long-term care insurance, prospective payment plans, catastrophic illness insurance, and tax policy changes such as expanding deductions.

EXAMPLE: Indemnity Insurance Carrier Financing

In a Texas project, designed to demonstrate the development of a system of care for children with special health care needs, an arrangement was made with the Medical Director of Blue Cross/Blue Shield of Texas for a pilot program to pay for the ambulatory services of the care management support team at four diverse sites in the State: Texas Children's Hospital, Houston (tertiary center); Kelsey Seybold Clinic, Inc., Houston (fee-for-service/HMO clinic); Providence Memorial hospital, El Paso (community hospital in large metropolitan area); and McAllen Easter Seal Society Clinic, Houston (secondary level center in large rural area). The Kelsey Seybold Clinic also serves as the site for a study of the Maxicare Health Plan to determine ways of paying for chronic care within an HMO setting.

Payment for ambulatory health team services by indemnity carriers is often limited to physician fees, with some physical and occupational therapy charges allowed. There is little or no coverage for patient education, medical social work services, nutrition services, or other support services. In the pilot sites, payment is based on composite charges for an initial assessment and composite charges for follow-up team visits. Evaluation of these pilot sites will determine the effectiveness of this financing mechanism in managing both the professional activities of the team and in charging for services.

EXAMPLE: Health Care Financing Project

Albert Einstein College of Medicine in New York is conducting a project on Financing Health Care for Chronically Ill and Disabled Children. The goals of the project are to develop reliable national estimates of the direct costs and sources of payment for hemophilia, autism, and severe mental retardation; to collect expenditure data from samples of families; to use these data to develop policy alternatives to the current financing system; and to improve the care of children with disabilities and control costs. The parents of national samples of children and young adults with autism and children and young adults with mental retardation provided information on the financing of their children's health care.

Preliminary findings on the patterns of public and private health insurance for children with autism and children with mental retardation show that these children are less well covered by private health insurance than the average American child. However, they are substantially better covered by public programs than the average child. A large percentage of the children under 18 are covered by Medicaid. Insurance gaps exist primarily in central city areas in the sample. Initial project findings will be augmented with full reports on insurance coverage, as well as reports on the use of health care services, variations in expenditures for medical and financial reasons, case management, and financial counseling.

EXAMPLE: MCH-Medicaid Managed Care in Utah

Two efforts are being made in Utah to improve outcomes and control

costs of care for children with special health care needs. In order to target scarce resources, the State Title XIX and Title V agencies (Medicaid and Maternal and Child Health) cooperated in a study of pregnant Medicaid recipients. The study showed that increasing the number of prenatal visits improves the outcome of pregnancy. Mothers who made fewer than six prenatal visits had a higher number of low birth weight babies than those making over ten visits. The average charge to Medicaid for low birth weight babies was \$63,000, while the charge for normal weight babies was less than \$3,000. This study was instrumental in the State legislature funding a cooperative prenatal care program between MCH and Medicaid to improve the outcomes of pregnancy among low-income women.

In another project, the State Medicaid program contracts with HMOs to provide managed care to their clients. MCH and Medicaid worked together to develop an innovative approach to ensuring quality care for children with special needs under this new system. Through an interagency agreement, all children with special health care needs are referred to State Title V programs for coordinated management of their specialized care, while the HMO continues to provide their regular health care. Data are being collected to evaluate referral patterns and cost-effectiveness.

EXAMPLE: PATHFINDER Project

PATHFINDER, in Minneapolis, Minnesota, is based on the premise that effective utilization of existing resources can improve the efforts of professionals, programs, and parents at the community level. PATHFINDER has successfully established linkages in communities through network building. The project has fostered a cooperative environment among agencies providing medical care, home services, and Medicaid financing for medically fragile children in Minnesota. PATHFINDER also has completed studies of several mechanisms of financing health care for children with chronic conditions.

A 1986 PATHFINDER study examined the health care coverage of chronically ill children in fee-for-service and in prepaid plans. The study included a survey of State high-risk insurance programs and the Minnesota Comprehensive Health Association Program to document utilization of

services by children with chronic illness who are enrolled in a State-mandated high-risk insurance program. The Minnesota Department of Human Services asked the project to establish a Task Force to develop a home care, community-based service model for Medicaid-eligible chronically ill children. A model service delivery system developed by the Task Force included: 1) definition of the target population, 2) client intake and case management responsibilities, 3) service definitions, 4) screening tools, and 5) quality assurance. The proposed program was implemented by Minnesota in the Spring 1986 as The Community Alternatives for Children's Programs. Children with chronic illnesses or disabilities, previously hospitalized to be covered by Medicaid, now can receive services out of the hospital.

ACTION STEP 7**Continue to Conduct Research and
Disseminate Information**

We need to continue collecting relevant data and information. But we must do more than add to our existing knowledge--we must put into practice what we learn. New ideas and mechanisms must be explored and implemented.

- Discretionary funds should be used to support research, demonstrations, and training.
- New and emerging issues must be studied, and the results of such studies should be carefully reviewed for application to the field.
- Families should participate in the development and review of research and demonstration projects.
- Wide dissemination of research and workshop findings will assure maximum application.

EXAMPLE: Classification System

Traditionally, children with special health care needs have been classified according to their medical diagnoses. Much of the data we have deals with children with specific diseases or conditions. Classification of a system based on functional capacity and service needs helps assure better planning, implementation, and evaluation of family-centered, community-based systems of services for children with special health care needs.

The National Maternal and Child Health Resource Center, under the project "Future Directions of Services for Children with Special Health Care Needs," has developed a new classification system which currently is being tested in several States by Title V State Programs for Children with Special Health Care Needs (formerly CCS Programs).

**EXAMPLE: Improving Services
Through Dissemination**

"Project Zero to Three" is based at the National Center for Clinical Infant Programs. The project's purpose is to improve services for disabled and at-risk infants, toddlers, and their families through activities such as national meetings, regional conferences, an interstate "buddy" system, consultations, and a newsletter. In addition to meetings and conferences on topics such as program evaluation and research utilization, several publications, reports, and a newsletter have been prepared and distributed by project staff.

Another project, the National Center for Youth with Disabilities in Minnesota, was established to maximize the potential of adolescents and young adults with disabilities. The Center's objectives are to develop a computer-based national resource library, to identify groups of health care professionals to consult with programs and agencies on health-related issues which affect adolescents and young adults with disabilities, and to facilitate the development of public policy to assist these youth with chronic health conditions.

**EXAMPLE: Electronic Networks and
Telecommunications Systems**

In 1984, the Department of Health and Human Services and the Department of Education formed a coalition to develop a national information and referral system at the University of South Carolina and at the Association of University Affiliated Programs on resources and services available for children with special health care needs. This system is comprised of local, State, and regional telephone and personal computer networks.

These networks are operated by parents; primary, secondary, and tertiary care providers; governmental agencies; and voluntary organizations on behalf of children with special health care needs and their families.

In addition, database networks are being developed at the Institute for Child Health Policy in Gainesville, Florida (A Computerized Management Information Database) and at a center for developmentally disabled individuals in San Diego, California. The San Diego system (A Computerized Patient Tracking and Information System) effectively tracks the delivery of services to children with special health care needs from Southeast Asian families.

These activities make it possible to combine telecommunications with computerization to improve the currency and accuracy of information available to family-oriented, community-based systems of care for children with special health care needs.

III. A CALL FOR ACTION

Children with special health care needs and their families face many challenges and burdens. Yet, we have the knowledge and resources to assist them in obtaining affordable, quality services. We have made progress, but can do much more to assure comprehensive systems of services for these children and their families.

Let us all make the commitment to these children and their families today, and move forward knowing that we have the information to guide us. In 1980 the Public Health Service issued *Promoting Health/Preventing Disease: Objectives for the Nation*. The Objectives for the Nation for 1990 are being updated for the year 2000. We will incorporate our task into the national objectives.

I am asking the Division of Maternal and Child Health to take the lead in collaboration with the American Academy of Pediatrics in assuring that our nation has a family-centered, community-based approach to care for all children with special health care needs. I ask all of you to work with the Division to accomplish this goal. With the collaboration of families, parent coalitions, State agencies, public and private health care providers, community support organizations, and the health care financing sector, we will be able to accomplish our task.

Therefore, I am asking:

- **FAMILIES**--to actively participate in caring for their children and to help shape health care policy and programs.
- **STATES**--to implement systems of care which support the strengths and needs of families, to assure the input of families at all levels of care, and to assure the adequate preparation of professionals for new collaborative roles.
- **PRIVATE HEALTH CARE PROVIDERS**--to develop systems which meet the needs of families and which encourage their

independence, by forging strong linkages between primary, secondary, and tertiary levels of care (physicians' offices, community health services, clinics, community hospitals, health maintenance organizations, children's hospitals, other teaching hospitals).

- ***THE HEALTH CARE FINANCING SECTOR***--to assure that all children with special health care needs have access to quality health care, and that support services are adequately funded to enable families to care for their children in their own homes and communities.

Improving the financing of care must remain a top priority in our commitment to insurance coverage for all. We applaud Medicaid in the public sector and insurers in the private sector for looking for mechanisms to improve and expand their coverage in cost-effective ways. We ask them to continue and strengthen these efforts.

We also must reach out to professionals in education, developmental disabilities, social services, vocational services, and mental health to assure that there is a coordinated approach to serving families. The Division of Maternal and Child Health will continue its partnership with other Federal agencies to facilitate a comprehensive approach to services that is family-centered, community-based, and culturally sensitive.

These major steps in building family coalitions, improving services for children and families within our States, and redirecting health care dollars in cost-effective ways will provide a tremendous force in accomplishing our goal of quality care for all children with special health care needs.

Let us work together to enable these children to receive the kind of care they need and deserve. We must build on our strengths and move forward. Using our knowledge and skills, and by cooperating, I know that we can make it happen--coordinated, family-centered, community-based care for all children who need special health care.