
Acknowledgements

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C. Everett Koop, M.D., Sc.D.
Surgeon General
United States Public Health Service

I. Introduction

This report is about children with special health care needs. As a parent and as a pediatric surgeon, I have felt a special commitment to these children and their families for over forty years. Children are the future of our nation and we must assure that children with special health care needs have the fullest opportunity to participate in all aspects of American society.

In 1982, I called a Surgeon General's Workshop on "Children with Handicaps and Their Families." The goals of the Workshop were to develop strategies for comprehensive services needed by children with special health care needs; to address the challenges and burdens of the families of these children; and to stimulate community resources.

Major Workshop recommendations included defining the scope of the problem; developing standards; developing systems of care; improving financing of care; incorporating principles of care into training for health professionals; and supporting research. Major actions taken since that time have implemented many of the Workshop recommendations, and showed the tremendous interest, caring, and concern of families and professionals involved in the care of children with special health care needs.

This report is a call to action. We are establishing a platform for a national agenda. It is time to draw our efforts together, recognize the progress we have made and chart a strong future course. I firmly believe that we have the knowledge, expertise and resources to make this happen. I know you will join me in our national campaign to improve the lives of children with special health care needs and their families.

II. Action Steps

This document focuses on a family-centered, community-based approach to health care. I believe this must be central to our thinking and to our efforts. I support the following elements of family centered care:

- Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.
- Facilitation of parent/professional collaboration at all levels of health care--care of an individual child; program development, implementation, and evaluation; and policy formulation.
- Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in a supportive manner.
- Implementation of comprehensive policies and programs that provide emotional and financial support to families.
- Recognition of family strengths and diversity, and respect for a variety of methods of coping.
- Encouragement of normal patterns of living in the home and community.
- Understanding and incorporation of the developmental needs of infants, children and adolescents, and their families into the health care delivery system.
- Encouragement and facilitation of parent-to-parent support.
- Assurance that the design of health care delivery systems is flexible, accessible and responsive to families.

In keeping with these elements, I have identified seven action steps that I believe can improve access to care and the quality of life for all children with special health care needs and their families:

1. *Pledge a national commitment to all children with special health care needs and their families.*
2. *Encourage building community-based service systems.*
3. *Assist in ensuring adequate preparation of providers of care.*
4. *Develop coalitions to improve the delivery of services.*
5. *Establish guidelines to control costs of services.*
6. *Encourage and support the development of adequate health care financing.*
7. *Continue to conduct research and disseminate information.*

For each of the action steps, I have included brief descriptions of some of the many worthwhile projects that have been undertaken since the 1982 Workshop. These examples show some of the exciting activities that are occurring as we work together to improve care for children with special health care needs and their families.

ACTION STEP 1**Pledge a National Commitment to
All Children with Special Health Care
Needs and Their Families**

We must commit to using the necessary resources to provide services and financial coverage for children with special health care needs and their families. Now is the time to use our knowledge and resources effectively, and to recognize that we must move forward.

Children with special health care needs include children with a broad range of disabilities and illnesses. Many different terms and classifications have been used to describe these children, and data from these various classifications are often not comparable.

According to the study conducted by the Vanderbilt Institute of Public Health Policy on Chronically Ill Children and Their Families, about 10-15 percent of children are estimated to have some form of chronic health condition, many of which are mild. Estimates from the National Center for Health Statistics 1985 National Health Interview Survey show that 3.7 percent of children under 18 years of age are either unable to engage in major usual activities or are limited in the amount or kind of usual activities. Smaller numbers are estimated to be dependent upon technology for sustaining life.

We do not intend to restrict our concern to a carefully defined population or to talk about precise numbers. Rather, we recognize that there are children with special health care needs (mild or severe; short-term, intermittent, or chronic), and that family-centered, community-based coordinated care must be available for them. In this way, families have access to care that is responsive to their changing needs.

It is important, however, to refine our data and information as we move ahead to:

- Create systems of care that are responsive to the strengths and needs of families.
- Ensure that these systems are flexible, are sensitive to cultural differences in families, and provide a range of options to families.
- Assure the availability of cost-effective, comprehensive services including social, emotional, and cognitive aspects of health care.
- Assure affordable health care.
- Enhance the skills of professionals in providing competent and compassionate care.
- Conduct evaluations of the effectiveness of supportive services for families.

EXAMPLE: ACCH Family-Centered Care Project

The goal of the family-centered care project at the Association for the Care of Children's Health (ACCH), in Washington, D. C., is to promote parent/professional collaboration and the use of a family-centered approach in all health care delivery systems.

Activities include assisting state agencies to encourage parent/professional collaboration; facilitating the use of policies and programs in hospitals and community settings that provide emotional and financial support for families; developing family-centered educational materials for health professionals; encouraging parent-to-parent support; developing a resource center on family-centered care programs; and enhancing the ability of parents to collaborate with health professionals and community organizations.

ACCH has convened networking meetings on family-centered care, presented family-centered material at several national and State meetings, and provided consultation to States on parent/professional collaboration and family-centered care policies. Also, family-centered guidelines and directories are being developed. In addition, ACCH has monthly mailings to over 500 parents and professionals, and is expanding its quarterly newsletter.

EXAMPLE: Southern Corporate Coalition

The Southern Regional Task Force on Infant Mortality was formed in 1984 to draw attention to the critical problem of infant mortality in the South and to promote preventive measures to reduce its incidence. The effort is a joint project of the Southern Governors' Association and the Southern Legislative Conference.

The Task Force published several reports which included a blueprint for action to reduce infant mortality and low birth weight in the South. One of the recommendations in the Final Report was to work closely with the corporate community to address this significant human resource problem.

The governors of the 17 Southern States in the Southern Governors' Association asked two corporate executives in each State to serve on a Corporate Coalition of the Southern Regional Project on Infant Mortality. The task of the Coalition is to identify economic benefits to be gained by business and the community at large from improved maternal and infant health care. In addition, Coalition members will examine ways to reduce infant mortality through corporate policies, and will make recommendations to other businesses in the South to promote improved maternal and infant health.

EXAMPLE: Project SERVE

Project SERVE is a collaborative effort of the Massachusetts Department of Public Health's Division of Family Health Services, the Harvard School of Public Health, and the Developmental Evaluation Clinic at the

Children's Hospital Medical Center in Boston. The project is managed by the Massachusetts Health Research Institute. The purpose of the project is to look at the most appropriate content, organization and financing of services for children with special health care needs and their families.

Data have been collected over a two-year period from consumers, advocacy groups, primary and specialty health care providers, and State human service agencies. A report entitled *New Directions: Serving Children with Special Health Care Needs in Massachusetts* provides a policy framework and summary of findings, and offers 14 recommendations.

A Platform for Reform in Massachusetts was developed for dissemination at a Statewide forum held as a final project activity. This forum focused on issues of financing health care for children with special health care needs and was aimed at mobilizing parents, providers, and policy makers to create new initiatives in this area.

ACTION STEP 2**Encourage Building Community-Based Service Systems**

Children deserve to live with their families in their own communities, and to share in the everyday experiences most Americans take for granted. We must make a commitment to provide the kinds of health care these children require, in ways that allow them to participate as fully as possible in all aspects of family and community life.

Children with special health care needs and their families require a wide variety of services from many agencies and professionals. These services are provided in different settings usually referred to as primary, secondary, and tertiary levels of care. These children need basic health services (primary care), usually provided by pediatricians, family doctors, or local health clinics in their home communities. They also require a variety of health, education, mental health, and social services provided at the community level (secondary care). These community-based services must be integrated to be responsive to the needs of families, and coordinated to prevent fragmentation, gaps in service, or duplication.

Not all services can be provided at the community level. More sophisticated care (tertiary level) usually is provided in children's hospitals, large medical centers and teaching hospitals. Strong linkages between the more sophisticated tertiary care and community service providers will enhance the continuity of care and help ensure cost-effective quality care within coordinated systems. At the State level, professionals and agencies must work together to support the development and improvement of these systems of care.

- Existing community-based systems of services for children with special health care needs must be made known and utilized, and

additional systems must be developed, expanded, and improved.

- In establishing these service systems, we must recognize the roles of three levels of health care--primary, secondary, and tertiary.
- Community-based service systems must assure that children and their families receive medical care, educational services, social services, mental health services, and a variety of family support services in the most facilitating environment.
- Community-based systems should facilitate coordination by providing case management services and individualized service plans.
- Primary and secondary level care should be community-based. There should be strong linkages between community level services and tertiary level care.
- Protocols must be established to assure the quality of care.
- Individual service plans and case management services can provide a method for monitoring quality of care and services.
- Both parents and professionals should participate in the development of standards for health care professionals, for facilities and for equipment. Mechanisms must be in place to assure that these standards are met.
- Families must play a strong role in all phases of quality assurance. Quality assurance mechanisms for community programs can benefit from the experiences in hospital settings.

EXAMPLE: Coordinate for Kids

A community collaboration approach for early intervention services,

called "Coordinate for Kids" has been developed in the State department of health in Oklahoma in conjunction with a university affiliated center in the region. Since the inception of the project, collaborative community teams have been established in seven communities. Task forces and councils have been formed to assure responsiveness to culturally diverse groups.

A State interagency task force has been established and is planning services for children with special needs. A Statewide needs assessment survey has been completed by the task force. In addition, a State information and referral system for children with special needs has been initiated. Funding for this system involved efforts of parents and private donors, as well as local and State agencies.

A computer-based communication network has been established to link community teams, parent groups, and State program personnel in Oklahoma with the University Affiliated Center in Dallas, Texas.

Collectively, the community teams are addressing the development of respite services, parent support groups, interagency case conferencing, and case management.

EXAMPLE: Michigan Locally Based Services Project

In 1983, the Michigan program for children with special health care needs, administered by the Division of Services for Crippled Children (DSCC) of the Michigan Department of Public Health, initiated a Locally Based Services (LBS) project to expand and improve community-based services for children with special health care needs. DSCC is using local health departments to deliver services to these children and their families in or near their home communities throughout the State.

A major component of the LBS project is the provision of case management services by local health personnel. A plan for case management is developed based on an interdisciplinary assessment of the problems and service needs of the child and the family. The case manager monitors the implementation of the case plan. The case manager also helps the

family obtain needed services, and coordinates services from multiple agencies, programs and providers. As a result of the project, families are gaining skills in problem-solving, management of services and self-advocacy.

EXAMPLE: The Hawaii Experience

Two projects in Hawaii are working closely together to address the needs of culturally diverse populations. A new project at the Hawaii Family Stress Center in Honolulu is facilitating primary care physician participation in preventive health care of children aged 0-5 from underserved, culturally diverse populations. The project promotes involvement of pediatricians in early screening and intervention. Goals include increasing the level of preventive health care, reducing severity of psychosocial problems and developmental delays, and increasing the physician's involvement as part of a team. The project functions within a home visitor project, "Healthy Start," designed for prevention of child abuse.

Another project has developed a community support network system for native Hawaiian children and their families. The Family Based Education Center Project at the Kamehameha School is conducting an extensive needs assessment of community service use and delivery within educational and health related areas for families of children 0-5 years. The project also is working with the State Title V programs to develop a State-wide model program, and is establishing linkages to the private practice community to universities, colleges and other voluntary, public and private resources in the State.

EXAMPLE: Iowa Regional Specialized Child Health Centers

Iowa has a system of regional, specialized child health centers, conducted by the "Iowa Program for Children with Special Health Care Needs," administered by the Iowa Department of Public Health. This system provides community-based services for children with special health care needs and receives funding from a variety of sources.

The regional centers are located throughout the State so they can provide services to children in or near their home communities. They are staffed by community service providers and are governed by local boards.

The centers are the locus for collaboration among health, social service, and education professionals from different agencies. They provide specialized evaluation services and coordination of services to children with chronic health problems and health-related educational and behavioral problems .

The Iowa General Assembly has appropriated Federal Title V funds and State general funds for the support of these centers. The area education agencies furnish special education staff for these centers and the department of human services contributes social work staff.

ACTION STEP 3**Assist in Ensuring
Adequate Preparation of
Providers of Care**

Family-centered, community-based service systems should be developed where children and their families live. These systems cannot function without personnel who have been adequately trained to provide family-centered, community-based care. To provide services in a community setting requires an orientation and specific skills that differ from those needed in other settings. Service providers who work in community-based programs must be trained to collaborate with families and other professionals to develop and implement care plans for children with special health care needs.

- An interdisciplinary approach to health care should be employed.
- More emphasis should be placed on the team approach to health care delivery in all settings.
- Health provider education should involve more course work and practical experience in the developmental needs of children with special health care needs and their families. Training programs should emphasize the influences of family, psychosocial, and environmental factors on health status.
- Health personnel training should include programs that provide contact over time with children with special health care needs and their families, particularly in home and community settings.
- Concepts and practice of family-centered care should be incorporated into the curricula used for training of health care provid-

ers. Families should participate in the development of curricula and preparation of these providers at the pre-service and in-service levels.

- Professional organization meetings and training programs should be models of parent/professional collaboration.
- Providers of care in community-based settings should share effective practices and innovative ideas with other professionals.
- State health, education, mental health and social services agencies need to address personnel training in family-centered, community-based care.

EXAMPLE: Chronic Illness Teaching Program

A Chronic Illness Teaching Program was initiated at Michigan State University in 1984. This primary care pediatric residency places a strong emphasis on the developmental and behavioral aspects of child care. The Teaching Program complements the disease management information received by the residents. The goal of the program is the training of pediatricians in the knowledge, attitudes, and skills needed to improve the care of children with chronic conditions. The central experience of the program is a three year, in-depth study of a child with a chronic condition and the child's family. The study acquaints the resident with the social, financial, educational, and psychological impact of a continuing condition on the child and the family.

EXAMPLE: Project BRIDGE

The American Academy of Pediatrics launched Project BRIDGE (Building Relationships for Infants with Disabilities through Group Education) to address the team needs of professionals who care for children with disabilities (birth to three years) and their families. The project has included improving team decision making practices, refining team function, increasing awareness of the benefits of early intervention and specialized

services, and improving coordination and continuity of service delivery. The project includes development of the in-service education program, and delivery of the program nationally and regionally.

EXAMPLE: The Connecticut IDA

The Connecticut Infant/Toddler Developmental Assessment (IDA) is a new way to measure infant/toddler development. It is a "second-level" assessment designed to bridge the gap between simple screenings and complex tertiary evaluations. The goal of the project is to improve community identification and assessment services for handicapped and at-risk children from birth to three years of age by providing complementary developmental assessment training for health, allied health and education professionals and other professionals who serve children. The assessment addresses the interrelatedness of the health, developmental, psychosocial, and family dimensions.

The IDA evolved from the experiences of several early childhood development specialists, physicians and public health specialists at the Yale University Child Study Center and was developed by a Statewide Interagency Task Force. Participants included primary care centers, specialty diagnostic clinics, neonatal follow-up services, early intervention programs, public school pupil personnel staff, and rehabilitation services. Project staff in the Hartford Department of Health, in partnership with the Health Services for Handicapped Children section of the Connecticut Department of Health Services, completed an IDA Procedures Manual, and developed curricula and training materials for classroom sessions as well as for clinical practice.

EXAMPLE: Continuing Education Institute

The Continuing Education Institute in Ohio offers both introductory and advanced continuing education programs. The purpose of the Institute is to maintain and strengthen leadership capabilities for medical, administrative, and other professional staff in key management positions of State Title V programs for children with special health care needs through-

out the country. Major areas addressed include program development, fiscal administration, public policy, and promotion and coordination. Faculty for the Institute include directors or representatives from Federal and State Title V Programs, the academic community, and guest speakers. The Institute provides time for informal sharing of information with the faculty, presenters, and colleagues.

ACTION STEP 4**Develop Coalitions to
Improve the Delivery of Services**

Collaboration and cooperation of parents, professionals from a variety of disciplines, and organizations help ensure successful delivery of family-centered, community-based services. Strong leadership and commitment are needed as individuals and groups work together to improve delivery of services.

- There must be cooperation among all sectors: public, private, and voluntary.
- All departments and levels of government should work together across agency lines and among community, State, regional, and national levels to ensure effective and efficient services.
- There must be coordination and cooperation among health care professionals at the primary, secondary and tertiary levels of care.
- Coalitions must be formed among organizations and groups representing all disabling conditions.

EXAMPLE: New Mexico Service Coordination

A New Mexico project seeks to improve the coordination of services for all chronically impaired children in the State. Special attention has been given to plans and procedures addressing the health care needs of Native American children and their families. The project has been successful in furthering parent/professional partnerships in planning services, establishing policy and in implementing programs. Family support

groups, using professionals as consultants, have emerged at the local level. Continuous planning, involving both parents and professionals, is underway for identification and tracking, case management, organization of medical services, family support systems, services for infants during the first two years of life, information and referral, and financing of care. The project has used a family-centered approach to activities. Parents have participated in the planning and conducting of a family stress conference and Native American parent-training workshops on rights under Federal legislation. This project has demonstrated the effectiveness of forming coalitions between parent and professional groups.

EXAMPLE: CAPP: Parent/Professional Collaboration

The Federation for Children with Special Needs in Boston directs a project called Collaboration Among Parents and Health Professionals (CAPP). The purpose of CAPP is to increase and enhance parent involvement in the health care of their children with special needs. The CAPP project works closely with a national technical assistance effort for parent training and information funded by the Department of Education.

Project goals are to prepare parents to assume integral roles in the health care of their children, to promote communication and collaboration among parents and health professionals, and to develop a national support system for parents.

CAPP activities have included development of training materials and workshops; conferences, meetings, and task forces focused on parent/professional communication and collaboration; regional outreach activities; and work with New England State departments of public health. CAPP also is developing models for parent involvement in health care settings.

EXAMPLE: Alliance of Genetics Support Groups

The Alliance of Genetics Support Groups is a coalition of voluntary organizations and professionals that grew out of a 1985 symposium. The

Alliance was formed to help genetics support groups become a unified force, to help the groups establish a link with research communities, to promote public education, and to provide a mechanism for sharing information.

The Alliance includes leaders from a dozen national organizations, as well as representatives of professional communities, such as health care, education, and law. The Alliance has published a newsletter and has held a national conference.

**EXAMPLE: The National Center for Networking
Community-Based Services**

The National Center Network project is based at the Georgetown University Child Development Center. The goal of this project is to achieve comprehensive, coordinated, community-based services for children with special needs and their families, through improved collaboration among public and private agencies and parents at all service levels.

The project maintains a network of leaders in health, mental health, and education; facilitates coalitions within States; provides training and technical assistance; develops knowledge and resources in areas such as family-centered care, financing of services, serving culturally diverse groups, and involving private pediatricians; and facilitates Federal interagency planning.

ACTION STEP 5**Establish Guidelines to
Control Costs of Services**

We can control costs while still ensuring the quality of services. Studies have shown that a comprehensive coordinated approach to care is cost-effective. We have demonstrated the feasibility and efficacy of this with specific diseases and conditions. Our challenge is to use this experience to develop a system of generic services at the community level which is linked to specialized services at the tertiary level.

- The nation will be served better by developing a generic system of care for all children with special health care needs than by repeating our experiences on a disease-by-disease basis.
- Case management to control costs and to ensure quality care must be developed and expanded in communities.
- We must find ways to pay for care at the community level.
- Careful studies must be conducted to document cost savings of community systems that replace fragmented patterns of service delivery.

Some examples of cost savings with specific conditions are given below.

EXAMPLE: Hemophilia Centers

The benefits of comprehensive care of persons with hemophilia have been shown through the Federally funded Hemophilia Diagnostic and Treatment Centers. The care provided through these regional centers