DEPARTMENT OF HEALTH & HUMAN SERVICES

The Surgeon General of the
Public Health Service
Washington DC 20201

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Vince L. Hutchins, M.D.
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Child Health
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Dear Dr. Hutchins:

The purpose of this correspondence is to inform you of the activities that have taken place with regard to the recommendations emanating from the Surgeon General's Workshop on Children with Handicaps and Their Families, convened in Philadelphia on December 13 and 14, 1982.

Workshop participants recommended that steps be taken to: (1) define the scope of the problem; (2) develop model standards; (3) develop systems of regionalized care; (4) improve financing of care; (5) identify areas of abuse potential; (6) incorporate into training curricula principles of care for children with disabilities; and (7) support research in the care of children with disabilities.

These recommendations are congruent with the existing policies, programs, and activities of the Public Health Service (PHS). The Division of Maternal and Child Health (DMCH) is the unit responsible for monitoring, encouraging, supporting, and evaluating the PHS activities in collaboration with other agencies in both the public and private sector that address the seven recommendations of the Workshop. These activities are summarized here for your information.

I. Defining the Scope of the Problem

The publication and dissemination of the Surgeon General's Workshop report in February and the National Conference on Chronic Illnesses in Children held in April by the Vanderbilt University Institute for Public Policy Studies have increased the public awareness of the scope of the problem of children with handicapping and chronic conditions. While the prevalence of individual disorders is generally known, prior to the Workshop there was little information available regarding the ventilator-dependent child. The Workshop stimulated a study in Illinois by the Crippled Children's Services (CCS) Program on the number of these children living in hospitals or at home. Based upon responses from 86 percent of the hospitals contacted, more than 120 children had required ventilator support for at least four weeks during the previous 12 months. Another 18 children had been discharged to home ventilator support. Pennsylvania is the only other State known to have this type of information.

Recent reports have indicated that the actual prevalance of chronic illness has been increasing over the last 20 years. Although several theories have been suggested for this phenomenon, the reasons for the growing number of babies born with some physical or mental defect is not known. A study being conducted by the Health Policy Program of the University of California at San Francisco is currently investigating the increase over the last 25 years in the number of days of limited activity by children.

The DMCH is currently making plans to convene a panel in September to further investigate the epidemiology of handicapping and chronic conditions of young children.

II. Developing Model Standards

This recommendation emphasized the need to develop models and standards that would be innovative, focus on the needs of the family, and reflect concern for the quality of life for each disabled child. In keeping with the spirit of the recommendation, two grants have been awarded to Iowa and Michigan. The Iowa project will investigate and analyze the variety of interactions occuring between health care professionals and children with disabilities, in order to: (1) determine an organizational framework to define those individual health care interactions; (2) determine principles of care to act as guidelines for those interactions; (3) delineate standards to guide the delivery of specific health care services for children with disabilities; and (4) publish and disseminate the results. The Michigan program, focusing on children with diabetes, will establish standards of care and develop a regionalized community health support system involving providers, voluntary and State agencies and the Maternal and Child Health (MCH) Services Block Grant mechanisms.

III. Developing Systems of Regionalized Care

Three grants have been approved to develop systems of regionalized care with a focus on ventilator-dependent children. These grants have been awarded to Illinois, Louisiana, and Maryland. The intent of all three projects is to transfer children from institutional settings to home or homelike settings through the use of multidisciplinary teams. The Maryland project, for example, will combine existing local, State and regional organizations to establish a private, non-profit organization to facilitate the discharge of ventilator-dependent children. All three projects focus on the need to develop and sustain a community-based support system. The projects are concerned with comprehensiveness, continuity of care and cost effectiveness. These projects will also help define the scope of the problem by providing new data on the numbers of children with this problem. We should learn also about some of the long-term consequences on children and their families.

In addition to these three projects, grants have been awarded to six States, Colorado, Georgia, Hawaii, Illinois, Ohio, and Texas, to facilitate the development of regionalized juvenile arthritis centers. A grant has been awarded to New York to develop a system of data collection and coordination of care and services to children with chronic illnesses in selected regions of the State. This system will then be replicated throughout the State in an effort to provide comprehensive, cost-effective services with followup care for all chronically ill children.

A work conference on interagency collaboration was held in June to share expertise around common issues and problems related to improving the quality of life for handicapped children and their families. This conference was sponsored jointly by the Department of Education and the Department of Health and Human Services and coordinated by the Georgetown University Medical Center's Child Development Center.

The conference was an outgrowth of three interagency collaboration projects that were funded at the Federal level by the Headstart Bureau, the Special Education Program (SEP), and DMCH to stimulate State support for local collaborative activities between health, education, and social service organizations.

In Iowa, a new type of integrated evaluation and planning clinic was created and became the model for community teams using public and private resources from health, education, and other agencies.

These grants reflect the intent of the third recommendation: to match the needs of disabled children with available resources in order to develop a system of care that addresses the social, educational, and health issues facing families of children with chronic handicapping conditions.

IV. Improving Financing of Care

While all seven recommendations from the Workshop are important, the issue of improving financing of care for children with disabilities is critical in order to assure that the needs of children can be met in the face of limited resources. To this end, a workshop on the financing of health care was held May 11-13, 1983 in Washington. The purpose of the workshop was to develop materials for the State Directors of MCH and CCS to enable better use of resources in providing for and financing health care of handicapped children. There were three stated objectives: (1) to provide a basis for State CCS programs to use in reviewing their leadership role in developing programs; (2) to identify problems with gaps in coverage from third party payers and to define ways to increase coverage to improve the extent and quality of services; and (3) to define creative and innovative ways to improve the availability of care and services from all sources. A report on the outcome of this workshop is in press and will be available later this year.

In addition, a meeting was held on June 14, 1983 with the Health Care Financing Administration to discuss the following: (1) reimbursement for ambulatory care of patients with chronic diseases; (2) reimbursement of comprehensive evaluations; (3) psychosocial problems that are not addressed by reimbursement mechanisms; and (4) the need for a better understanding about and reimbursement for care at home. These issue areas were developed as a result of the past success of the hemophilia program which is based on the idea of ambulatory care and are useful as examples of improved patient outcome, and reductions of inpatient admission, length of hospital stay and total health care costs. The financing of health care for handicapped children and those with chronic conditions continues to be a concern of the Administration.

V. Identifying Areas of Abuse Potential

This recommendation calls for the elimination of unnecessary, duplicated or inappropriate services to assure quality care and to control costs. These issues have been addressed to some degree in the grants mentioned earlier dealing with the development of model standards and regionalization of care. It is important to note that increased utilization of either services or products does not necessarily indicate abuse. In the case of self infusion, for example, under the hemophilia program of ambulatory care, the use of blood products has increased. Comprehensive care is presented as controlled care in which both children and their parents must qualify through psychosocial screening and training in self infusion. Blood product is prescribed only if a log of usage is accurately maintained at home and reviewed periodically by program staff. In this instance, the potential for abuse is reduced through monitoring by qualified professionals, and by the development of standards of care while continuing to provide children and their parents with information and optimal services. This model from the hemophilia program will be useful in the development of other programs for ambulatory care to prevent potential abuse.

VI. Incorporating Principles of Care for Children with Disabilities Into Training Curricula

On June 27, 1983, an ad-hoc committee was convened to further the development of collaborative efforts between DMCH and SEP to determine the needs in providing training for professionals and parents with the focus on children in the 0-3 age range with discernible handicapping conditions. Participants included pediatricians, obstetricians, neonatologists, perinatologists, special educators, parent advocates, and media specialists.

The DMCH has awarded a grant to the National Center for Clinical Infant Programs for a project designed to assist 10 selected States in their efforts to improve services for at-risk and disabled children and their parents in the first three years of life. This project (Project Zero to Three) will use meetings, consultations, technical assistance, and consensus building as tools to begin construction of a framework for knowledge sharing.

A conference, "Education of Pediatricians for the Ongoing Care of Children with Special Health Needs," was held in New York, July 26-28, 1983. Small working groups examined the role of the pediatrician with respect to: (1) the care needs of children with special health problems; (2) ways in which current educational patterns foster or obstruct the development of individuals to carry out these roles; and (3) directions for enhancing pediatric training in the future. The conference brought together individuals in leadership positions in a variety of fields who can contribute important perspectives to improving the training of pediatricians to deal with the needs of this population. A summary statement from the conference will be available in early Fall. In addition to participants, the statement will be sent to Chairmen of all Pediatric Departments, selected Foundations and other interested parties.

At the present time, grants are being reviewed in DMCH in the area of continuing education. The call for these grants emphasized the need for the incorporation of principles of care for children with disabilities into training curricula.

VII. Supporting Research in the Care of Children with Disabilities

In keeping with the intent of this recommendation, the Vanderbilt University Study identified five broad areas of research. These areas are: (1) basic biomedical; (2) clinical studies; (3) developmental and psychosocial; (4) clinical epidemiology; and (5) health services. This study suggests that future research be conducted using a non-categorical approach with multidisciplinary, collaborative, and longitudinal studies of the areas of the interactions between these five research areas.

A more detailed description of these activities will be included in the one year followup report to participants. It is clear that the recommendations are valuable and have stimulated activities in program development and policy discussion to improve the quality of care and services to children with chronic and handicapping conditions and their families.

Thank you for the part you have played in the planning of the Workshop and the formulation of these recommendations. I look forward to your continued participation in this important endeavor.

Sincerely yours,

C. Everett Koop, M.D.
Surgeon General