children's hospital
national medical center 111 MICHIGAN AVENUE, N.W., WASHINGTON, D.C. 20010 • (202)

DEPARTMENT OF CHILD HEALTH AND DEVELOPMENT, GEORGE WASHINGTON UNIVERSITY
CHILD HEALTH CENTER • RESEARCH FOUNDATION OF CHILDREN'S HOSPITAL

May 14, 1982

C. Everett Koop, M.D.
Surgeon General and
Deputy Assistant Secretary for Health
Department of Health and Human Services
Hubert H. Humphrey Building
Suite 716 G
200 Independence Avenue, S.E.
Washington, D.C. 20201

Dear Dr. Koop:

I was pleased to receive your letter of January 28, 1982 concerning your decision to move our request for consideration of our Home Care Project to your Planning and Evaluation Committee. I thought it might be appropriate to summarize our discussion.

Because of progress in medical science, the number of infants and children with special needs has increased dramatically in recent years. Children with chronic illness or handicapping conditions who would have died a decade ago now not only survive, but also may not need continual or frequent institutional care, provided that suitable home care services are available. Coordination of care for the multifaceted and sophisticated needs of these children, however, has not kept pace with technical progress. Furthermore, the families of infants and children with multiple handicaps are often the very persons who have the most difficulty taking advantage of the current system of care, because of language or cultural difficulties, the complexity and disjointed nature of the delivery system, or the lack of attention to their particular needs.

Insufficient funding for home-based services also poses a major barrier to the development and expansion of needed programs. Traditional sources of third-party reimbursement are generally not provided for the educational, psychological, and social needs of the child with multiple handicaps. Furthermore, although federal guidelines now allow states to apply for waivers for Medicaid reimbursement for some of these services, many of them, like the District of Columbia, are reluctant to do so because they fear they will be unable to meet the ensuing increased demands for care.

Thus, health planners and policy makers often fail to realize the potential advantages of home care to children, families, and society alike. Instead of seeing it as the most humane and effective way of caring for the chronically ill child, they see it as an increased financial burden. They also lack the perspective needed to realize that home care is ultimately the most cost-effective health care alternative, since it involves investing in people rather than in buildings or equipment.

At Children's Hospital National Medical Center, we are convinced that home care offers the best and most economical means of assuring a healthy and normal life for the child with chronic illness or handicapping condition. Our Home Health Care Team was established in 1981 with seed money from a foundation in the Washington area. The primary purposes of our program are to demonstrate how comprehensive, cost-effective home-based care may be delivered to multiply handicapped and high-risk children and infants, and to bridge communication and health care gaps between the hospital, families, and community agencies. We offer therapy, nursing, social, educational, and counseling services to multiply handicapped children and their families. Our staff includes a physician whose specialty is pediatric rehabilitation, a rehabilitation coordinator, a nurse, a physical therapist, an occupational therapist, an education coordinator, a social service worker, and a psychologist. During the first eight months of our program we have seen a total of 42 children, each of whom is seen between two and three times per week.

During the first year of our work with home care, we have identified several major problem areas. Within the District of Columbia very often programs are not comprehensive enough to meet all of the clients' needs: an educationally based center may offer good infant teaching, for example, yet the medical and rehabilitation services may be lacking. There are no other home-based services in the District of Columbia that are able to manage a child who requires nursing, physical therapy, occupational therapy, social work, educational and psychological testing and support. In order to offer children the services they need many of the community agencies are forced to contract out with private vendors. This unfortunately leaves a departmentalized rather than a coordinated interdisciplin plan of care, where quality of care is difficult to assess and control.

Many of these problems are not unique to Washington, D.C.; they are shared by health providers and children not only in other cities but also in more rural areas. One of the long-term goals of our Home Care effort is therefore to develop guidelines for the delivery of quality home care that

may be appropriate for utilization throughout the country. To do so, however, we must seek additional funding to expand our population base and collect more data.

- We need to collect information on the effectiveness of home health care as a continuation of care or as an alternative to hospitalization so that we can appropriately plan for the extended health care needs of a pediatric community.

- We need data on what levels of care (intensive, intermediate, maintenance, prevention, or outreach) are most necessary in order that we may be prepared to offer the most skilled care necessary. It is in the areas of intensive and intermediate care that the highest degree of skills are required. This is the area of expertise where a hospital-based, subspecialty interdisciplinary team can best demonstrate a unique contribution to the delivery of health care.

- We need to know which service components of a home care program are most necessary. Our core structure, which includes a nurse, physical and occupational therapists, a social worker, an educator, and a psychologist, may not prove to meet all the needs of our population. The core structure of each interdisciplinary team must meet the most critical needs of the pupulation served in order to realize a goal of successful non-institutional extended care. Other services may include physician, 24 hour nursing, homemaker, home health aide, nutrition, speech therapy, and inhalation therapy.

- We need to know the difficulties related to the successful utilization of home care. Are there problems of skill, communication, delays in visits or frequency of visits, delays in obtaining necessary equipment or supplies, financial considerations, or psychosocial problems surrounding the caretaker's ability or willingness to participate in the program?

- We need to develop demographics in order to target the most needy, in order that we use our service efficiently and effectively and continue to utilize other established areas of the health care delivery system to their greatest advantage.

In this age of limited finances we cannot continue to spend money on mortar and bricks to build institutions of care, but rather put our money in people taking care of people. We must allow ourselves the open ended system of the home and family to serve the dependent of our society.

With increased financial support, our pediatric home care project can play a vital role in developing standards for effective interaction between the family, the community, and the health care system.

I appreciate the opportunity to share my Team's goals and philosophy with you, and would welcome any suggestions that you make. Please contact me if you have any questions or comments concerning our program.

I look forward to hearing from you in the near future. Thank you for your interest in our project.

Sincerely,

Ruth H. Bock

Ruth H. Bock
Project Coordinator
Home Care Team