

Summary of the Workshop

The Call to the Workshop

In the summer of 1982, Surgeon General, C. Everett Koop, M.D., requested that a Workshop on Children with Handicaps and their Families be convened to seek out ways to lessen the handicaps imposed on disabled children and to promote child and family self-sufficiency and autonomy. The workshop was held at The Children's Hospital of Philadelphia on December 13 and 14, 1982. Over 150 individuals including handicapped patients, their families and those involved with their care, were invited to participate in the conference. An additional 100 people attended parts of the proceedings because of their interest in the welfare of handicapped children. All of the participants paid their own expenses or were supported by their own institutions. Financial assistance was provided for participating patients and parents.

The Workshop was called in response to the revolutionary transformations in medical technology which have taken place during the past four decades. Discoveries and applications in the fields of antibiotics and other drugs, in vaccines, in computerized imaging procedures, in life-support and monitoring, in laboratory techniques, and in the understanding of basic physiology have altered the prognosis for innumerable children. The baby who is born minutely premature, and the infant with severe congenital defects of the major organs or skeleton, and the child who is damaged by severe trauma or infection can now be supported by the combination of high technology and trained medical personnel. Many of these children now survive, and most of those who do can look forward to a productive life, though often impeded by residual disability.

Modern American society has geared itself to almost unlimited support of this technology. But support for the essential services systems outside the tertiary care environment has not kept pace for the increasing numbers of children whose lives are being saved. Technology is expensive, essential support services are also expensive, and funds are limited. Numbers of questions require consideration. Can we maintain the technological support, yet improve the essential services with the funds available? Do we need more funds? Can we find ways of redistributing the funds now being spent? Can we devise strategies for providing more humane service with fewer dollars?

Those attending the workshop concentrated on the severe, specific problems of the ventilator-dependent child, and the findings for this prototype were extrapolated for their implications for all handicapped children.

Presentations of programs in Illinois, New York, and Pennsylvania explored problems and progress in meeting the needs of increasing numbers of ventilator-dependent children. A parent, Mrs. Betty Wartenberg, presented a summary of the life of her nine-year old son. She gave an account that recalled the years on ventilator support in an intensive care unit, the disruptions to family unity, and of the remarkable progress made after his transfer to home care.

Following these presentations the participants were assigned to working groups where a mix of disciplines were used to assure an interchange of ideas and perspectives. Parents met insurance people, government executives saw and talked with handicapped patients who were in wheelchairs and on ventilators,

executives of service organizations walked the acute and intermediate wards of the hospital and interacted with children who have lived there all their lives, 3 or 4 years; legislative aides participated with physicians and hospital administrators. During this brief time a mechanism evolved which cut through the intermediaries of typed letters, impersonal phone calls and layers of formalization.

A consensus of the working groups' deliberations was reported to a final plenary session, which marked the close of the workshop.

Synthesis of the Deliberations and the Surgeon General's Responses


The summaries and recommendations of the workshop groups reveal an overwhelming diversity of concepts and directions to be considered. Many ideas arose repeatedly during the two days of discussion and can be grouped within broad categories:

- . Developing regional systems of care
- . Defining the scope of the problem
- . Developing model standards for quality assurance
- . Incorporating principles of care for children with disabilities into current education curricula
- . Identifying areas of potential abuse
- . Supporting research on the care of children with handicaps
- . Improving financing of the kinds of care these children and their families need

While the workshop did not focus specifically on ethical matters, the effect of each participants set of social values was always apparent during discussions. Interaction was influenced by each persons' values, conscious or not, stated or unstated. Throughout the process one quality, humaneness, permeated all. Humaneness, thus, was a common thread and a universal motivation. Every expression of thought seemed to emanate from the theme, "what is best for the child?"

Continuing Mission of Workshop

In declaring the workshop ^A success and accepting its recommendations the Surgeon General expressed his belief that the eventual outcome will be better health care for a more diverse ^{S AS WELL AS} ~~and~~ an increased number of children with disabilities. ^{DR. KOOP} He stated: "Where we have it in our power, we hope to make their handicaps temporary, or, at least to ameliorate their severity. We will be using a variety of techniques to continue the momentum which has developed at the workshop, and I will report back to you as we make progress on the various suggestions you have passed on to me as Surgeon General.

 The Department of Health and Human Services has a very strong commitment to improve services to disabled children and their families. And, as long as I am Surgeon General, disabled children have a very strong advocate in the Public Health Service. "