EDITORIALS

Meeting the Health Care Needs of Children with Disabilities

Over the past four decades, revolutionary transformations in medical technology—advances with respect to antibiotics and other drugs, vaccines, laboratory techniques, computerized imaging processes, life-support and monitoring systems, and understanding of basic physiology—have altered the prognosis for innumerable children with grave medical problems. The baby born far too soon, the infant with severe congenital defects of major organs or skeleton, the child impaired by severe trauma or infection—all these can now be supported by the combination of advanced medical technology and trained medical personnel. Today, many such children are surviving, and most of those who do can look forward to a productive life, although they are often impeded by residual disability.

But while modern American society has geared itself to almost unlimited support of medical technology, there has been a significant lag in the development of essential support services for children with handicaps and particularly for their families. Yet an estimated 1.2 million American children under the age of 17 are limited in a major life activity because of chronic conditions—and this figure does not include those whose problems are severe enough to require them to live in hospitals or other institutions.

Technology is expensive; essential support services are also expensive—and funds are limited. Many questions require consideration: Can we maintain support for technology, yet improve essential services, with the funds that are now available? Do we need more funds? Can we find wise ways to redistribute the funds that are now being spent? Can we devise strategies for providing more humane service with fewer dollars?

To consider these questions and related issues, the Surgeon General's Workshop on Children with Handicaps and Their Families was convened at Children's Hospital of Philadelphia, December 13–14, 1982. More than 150 persons participated: handicapped patients and their families as well as national experts in habilitative medicine, nursing, health care administration, third-party reimbursement, health planning, and health care financing. Some 100 additional persons attended parts of the proceedings because of their interest in the welfare of handicapped children.

Using the specific circumstances of the ventilator-dependent child as a model, workshop discussions focused on the question, Can quality care for children with severe medical problems be provided in a home and community setting, rather than in a high-technology medical center?

Why was the ventilator-dependent child used as the model? First, care of these children is perhaps the most complex endeavor that we currently undertake in rehabilitation. Second, it is the most expensive—not only on a per diem basis but also long term, until these children can be weaned from ventilator dependence. Finally, if we can solve the many problems surrounding required care for such youngsters and their families, we can probably find ways to solve the less complex, less expensive needs of children with other handicaps. Children's Hospital of Philadelphia was chosen as the site of the workshop because the staff's experience in home care for ventilator-dependent children is the most comprehensive in the country.

One of the parents at the workshop gave a moving account of the life of her 9-year-old son, recalling the years he had spent in an intensive care unit on ventilator support, the consequent disruptions to family unity, and the remarkable progress the child had made after his transfer to home care. Data presented about programs in Illinois, New York, and Pennsylvania that are striving to meet the needs of increasing numbers of ventilator-dependent children were extrapolated for their implications for severely handicapped children.

Following the formal presentations, workshop participants were assigned to working groups in which a mixture of disciplines assured an interchange of ideas and perspectives. Parents traded views with insurance representatives; government executives talked with handicapped patients in wheelchairs and on ventilators; executives of service organizations walked the acute and intermediate care wards of the hospital, meeting children who had been hospitalized all their lives; legislative aides debated issues with physicians and hospital admin-

istrators. Throughout these discussions, one quality —humaneness—was a common thread and a universal motivation. Every expression of thought seemed to emanate from the theme, What is best for the child?

The workshop's focus on the ventilator-dependent child provided a concrete, meaningful springboard to consideration of the needs of all disabled children and their families. Thus, the recommendations generated by the workshop have broad implications, as the following outline indicates.

1. *Define the scope of the problem.* More definitive information is needed about the numbers and types of disabilities experienced by infants, children, and young adults in this country, as is a better assessment of the impact of these statistics on social, health, educational, and family-related needs. Considerable progress has been made in some areas, but a system integrating functional, social, health, and family concerns remains to be defined, accepted, and consistently used by all service personnel and agencies.

2. *Develop model standards for care.* Model guidelines and standards must be developed for identifying, evaluating, and providing coordinated care at all levels for persons with disabilities. Care standards for cohorts of disabled children with special needs must be superimposed on generic care standards for all children with disabilities. All standards must focus on family needs, with an eye to innovation and with compassion and concern for the quality of life of each disabled child. Careful consideration must be given to identifying methods of care that conserve and effectively use scarce fiscal and human resources.

3. *Develop systems of regionalized care.* Matching the needs of disabled children with available resources will demand a system of care that reflects concern for social, educational, health, and family issues and that can focus on times of transition in disabled children's lives. Targets for concentration of resources will be determined by such factors as incidence, prevalence, and severity of the disability; location of the needed service; and other geographic and demographic considerations. Traditional methods will suffice for providing community-based health care for infants, children, and young adults with relatively uncomplicated disabling conditions; however, regionalized care will be required for disabled children who have life-threatening conditions or require highly specialized tertiary care.

4. *Improve financing of care.* The service system must reward providers and consumers using out-of-hospital facilities that are close to patients' home communities and that meet established standards of care. Funding mechanisms must also be made available for expensive out-of-hospital technical equipment that reduces the length of hospital stays. Planning and coordination of services for patients with complicated and serious disabilities must be recognized as a legitimate reimbursable expense.

5. *Identify areas that have potential for abuse.* Both actions and inactions can contribute to abuse of the care system for the disabled child. Elimination of unnecessary, duplicative, or inappropriate services promotes quality care and controls costs. Standards and regulations must be developed and monitored by qualified professionals familiar with service delivery issues.

6. *Incorporate principles of care for disabled children in training curriculums for health professionals.* There is a need for incorporation of clinical experiences relating to the care of disabled infants, children, and young adults into all levels of preservice and inservice education for health professionals. Teaching models should enhance professional satisfaction in caring for disabled children. Methods to improve communication by professionals with patients, patients' families, and coworkers must be components of the training program.

7. *Support research on the care of children with disabilities.* Although our scientific understanding of many disabling diseases and conditions is sophisticated, we need to learn much more about optimal methods of health care delivery for disabled children. Among the subjects research should address are ways to provide better training for health professionals in evaluative methods and treatment techniques, methods for improving communication and coordination of skills among professionals, techniques for immediate dissemination of new information concerning the care of disabled children, and ways to improve financial reimbursement procedures. Increasing concern for fiscal responsibility and accountability will point up the wisdom of devoting significant portions of available resources to expand research and development endeavors.

A full report on the workshop has been published by the Office of the Assistant Secretary for Health and will be widely distributed through State maternal and child health and crippled children's services directors as well as through voluntary agencies.

I am confident that the workshop's eventual outcome will be better health care for a greater number —and a greater diversity—of children with disabilities. The Department of Health and Human Services has a strong commitment to improve services to disabled children and their families. We will be using a variety of techniques to continue the momentum developed at the workshop, and I will report back to you as we make progress toward achieving its goals.

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An Operational Classification of Disease Prevention

Three decades have elapsed since a working group under the Commission on Chronic Illness proposed the classification of disease prevention into the categories primary and secondary (*1*). An additional term, "tertiary prevention," has gained currency since, and the classification is now ubiquitous in textbooks of epidemiology and preventive medicine. These classes are summarily defined as primary—practiced prior to the biologic origin of disease; secondary—practiced after the disease can be recognized, but before it has caused suffering and disability; and tertiary—practiced after suffering or disability have been experienced, in order to prevent further deterioration. This classification stems from an era when biomedical research was almost exclusively the province of the laboratory scientist, and concepts of health and disease were principally mechanistic. In recent years, the growth and success of epidemiologic research on chronic disease have introduced a large body of nonmechanistic scientific knowledge germane to disease prevention. We are conversant with statistical associations between risk factors and clinical events and have accepted a battery of criteria for judging whether or not the association represents causation (*2*). The primary-secondary classification is attractive and simple, but it does not serve to distinguish between preventive interventions which have different epidemiologic justifications and require different strategies for optimal utilization. As the Department of Health and Human Services moves to focus attention on and increase its efforts in disease prevention and health promotion, it is appropriate to consider an alternative approach to classification that is more closely linked to the practical considerations that govern proper application of preventive interventions.

In the old scheme, the distinction between primary and secondary prevention depends on our identification of the biologic origin of disease. While the biologic origin of acute infections and injuries may be clear-cut, the same is not true of the chronic diseases that now constitute our major causes of disability and death. Does myocardial infarction begin with the first pain, or with the first arterial wall lesions which may have developed in youth (*3*)? Does cancer stem from the initiation event, or only from the occurrence of effective promotion (*4*)? As more is learned about multifactorial chronic diseases with long periods of latency, the concept of biologic origin of disease becomes progressively more diffuse. We also become entrapped by semantic distinctions that have more historical than rational scientific justification. Consider the three common clinical situations of asymptomatic but abnormal elevations of blood sugar, blood pressure, and serum cholesterol. They are logically identical in that none produces discomfort or disability, each has serious diagnostic significance for future clinical events, and each is susceptible to intervention. Yet we commonly call diabetes and hypertension diseases, but refer to hypercholesterolemia as a risk factor. Dietary management of hypercholesterolemia is often called "primary prevention of heart disease," but prescription of a diet for diabetes or a drug for hypertension is viewed as treatment, or possibly secondary prevention.

A second disadvantage of the 1952 scheme, in our opinion, is that the terms "primary" and "secondary" suggest an ordinal value. Although it was not the intention of the Commission to suggest that primary is preferable, and secondary is second rate, this impression may develop, particularly among lay persons who may have responsibility for important decisions that bear on preventive programs. Careful quantitative analysis of benefits, costs, risks, and effectiveness frequently reveals that a preventive intervention is best applied only to a high-risk group, the evidence of high risk being a finding that can be related to the biologic origin of disease. Though "secondary," this may well be the optimal preven-