REPORT OF THE SURGEON GENERAL'S WORKSHOP ON CHILDREN WITH HANDICAPS AND THEIR FAMILIES:
CASE EXAMPLE: THE VENTILATOR-DEPENDENT CHILD

Presented by the
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Health Resources and Services Administration
Bureau of Health Care Delivery and Assistance
Division of Maternal and Child Health

In Conjunction With
THE CHILDREN'S HOSPITAL OF PHILADELPHIA

DECEMBER 13TH AND 14TH 1982

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It is profoundly important for our society that we tend to these issues of disabled children, that these children not be forgotten or pushed aside, and that we retain our belief in the strength of the American family.

—C. EVERETT KOOP, M.D.
SURGEON GENERAL

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Photos Courtesy of The Children’s Hospital of Philadelphia
December 10, 1982

Dear Friends:

This brings my special greetings to each of you participating in the Surgeon General's Workshop on Children with Handicaps and Their Families.

I want to encourage you in this very important endeavor. For many children facing physical difficulties, there is no place like home and no substitute for being close to a loving family. I am hopeful that ways can be found to make it possible for many more children on life-supportive devices to go home. It will mean more than we know to both the children and their parents. The entire family will derive untold strength from being together.

I thank you from the bottom of my heart for your interest in helping our special children. You have my warmest best wishes for a successful workshop.

Sincerely,

[Signature]

The Surgeon General's Workshop on Children with Handicaps and Their Families
The Children's Hospital of Philadelphia
Philadelphia, Pennsylvania
PREFACE

The Surgeon General's Workshop on Children With Handicaps and Their Families recognizes our continuing interest in assisting the family as the prime source of nurture, support, protection, and guidance to the growing child. Children with handicaps and their families frequently require long-term medical, social, educational, vocational, habilitative, and community service assistance. This concept is essential to the provision of comprehensive services to children with special needs.

Families of these children, including siblings, often need significant psychosocial support, but community support services are often lacking or not visible. Without the needed support, the family will have difficulty in helping the child, a growing individual moving through predictable developmental stages, achieve maximum development within the limitations imposed by a disability.

The goal of the participants at this Surgeon General's Workshop was to develop recommendations for strategies to recognize the special burden and challenges borne by the parents and siblings of children with disabilities and to stimulate the provision of resources to safely support these children in their communities. The achievement of this goal will, ideally, minimize the problems of children with disabilities.

C. Everett Koop, M.D.
Surgeon General
PLANNING COMMITTEE

Planning Committee for the Surgeon General’s Workshop on Children With Handicaps and Their Families

WORKSHOP CHAIRMAN  Robert G. Kettrick, M.D.
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The Children’s Hospital of Philadelphia

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Medical Officer
Division of Maternal and Child Health
Department of Health and Human Services

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Presidential Correspondence
The White House
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Division of Maternal and Child Health
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Phyllis Zucker, M.P.H.
Chief, Resources Branch
Division of Policy Analysis
Office for Health Planning and Evaluation
Washington, D.C.
WORKSHOP PROGRAM

December 13, 1982

8:00 a.m. - 11:45 a.m.  Plenary Session
Joseph Stokes Auditorium
The Children's Hospital of Philadelphia

Presiding
Merle G. McPherson, M.D.
Chief, Habilitative Services Branch
Division of Maternal and Child Health
United States Department of Health and
Human Services—Public Health Service

Welcome
Noel E. Kroncke, President
The Children's Hospital of Philadelphia

Ginny Thornburgh
Advocate for the Handicapped

James A. O'Neill, Jr., M.D.
Surgeon-in-Chief
The Children's Hospital of Philadelphia

Thomas W. Langfitt, M.D.
Vice President for Health Affairs
University of Pennsylvania

Robert G. Kettrick, M.D.
Director, Pediatric Intensive Care Unit
Intermediate
The Children's Hospital of Philadelphia

8:30 a.m.
Keynote and Charge
C. Everett Koop, M.D.
Surgeon General

9:00 a.m.
Ventilator-Dependent
Children
The Problem
Robert G. Kettrick, M.D.

9:45 a.m.
The Child at Home
Mrs. Bette Wartenberg
Parent of a Ventilator-Dependent Child
Joliet, Illinois

10:45 a.m.
Comprehensive
Regionalized Care:
New York Experience
Mathew H.M. Lee, M.D.
Professor and Director, Howard A. Rusk
Respirator Rehabilitation Medicine
Department of Rehabilitation Medicine
New York University Medical Center
Goldwater Memorial Hospital
New York, New York
11:15 a.m.  
Towards a Consortium: The Illinois Approach

11:45 a.m.  
Question Period

12:15 p.m.  
Presiding

Invocation

Children with Disabilities—Implications for Care

2:00 p.m.  
Background for Work Group Discussion

2:30 - 5:30 p.m.  
December 14, 1982

8:00 a.m.  
Work Groups

2:00 p.m. - 5:00 p.m.  
Plenary Session—Summation

Presentations from Work Groups

Synthesis of Recommendations

Presentation to Surgeon General

Acceptance of Recommendations

Conclusion

Allen I. Goldberg, M.D.  
Director, Division of Respiratory Care  
Children's Memorial Hospital  
Chicago, Illinois

Arthur F. Kohrman, M.D., Director  
LaRabida Children's Hospital and Research Center  
Chicago, Illinois

Eugene Bilotti, Administrator  
Supplemental Security Income (SSI) Disabled Children's Program  
Springfield, Illinois

Morning Speakers

C. Everett Koop, M.D.

The Reverend William Atkinson, O.S.A.

Alfred Healy, M.D.  
Chairman, Division of Developmental Disabilities  
University Hospital School  
University of Iowa  
Iowa City, Iowa

Phyllis R. Magrab, Ph.D.  
Director, Child Development Center  
Georgetown University Hospital  
Washington, D.C.

Robert G. Kettrick, M.D.

Richard D. Wood, Chairman  
Board of Managers  
The Children's Hospital of Philadelphia