SERVICES FOR HANDICAPPED CHILDREN

A Guide to general principles and practices for public health personnel

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and practices for public health personnel

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Prepared and authorized for publication

by the Committee on Child Health of the

American Public Health Association

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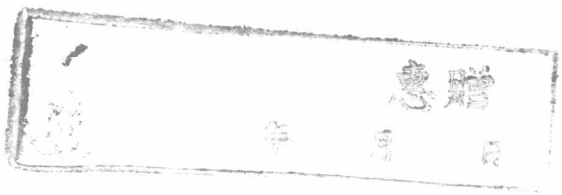

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FOREWORD

In 1949 and 1950, the Committee on Child Health of the American Public Health Association, realizing the need for some kind of practical guidance in establishing community programs for handicapped children, began exploring ways in which such guidance might be provided. The Committee believed that much of the prevailing information about the needs of children had not been satisfactorily evaluated; frequently it was inaccurate; and often the best knowledge was unavailable to those who could use it. Significant facts needed to be drawn together, discussion provoked, opinions formulated, and agreement reached on how children may best be served through community action.

It was apparent from the start that good practices in the care of children who are handicapped by specific disabilities can be developed best where general principles of community planning are un-

derstood and are carried out. It was also clear that knowledge and practice of general principles in community organization are not in themselves sufficient for the development of sound programs for specific types of handicapping conditions. More concrete guidance is needed. Thus, in 1951 a subcommittee was appointed to draw up a statement of general principles, and advisory groups were selected to prepare outlines of public health practice in eleven special fields.

This document is the first of the series. It deals with problems common to various handicapping conditions, discusses the general philosophy of community services for handicapped children, and outlines guiding principles and practices on which programs may be based. The other Guides in the series will attempt to illustrate the application of these general practices and principles in planning services for children with such special problems as:

Cerebral palsy
Cleft lip and cleft palate
Dentofacial handicaps
Diabetes
Emotional disturbances
Epilepsy
Hearing impairment
Heart disease and rheumatic fever
Orthopedic and neuromuscular handicaps

Visual impairment and other eye disturbances

Selection of these categories was based on their importance as public health problems, including:

Size and extent of need

Urgency of the situation

Professional and public interest

Possibilities of achieving results through community effort

Because this series of Guides is concerned with services for separate groups with particular problems, the Committee wishes to reemphasize that the development of programs for handicapped children is approached best as one part of a total community effort. The basic health and education services which are essential in meeting the common and ordinary needs of all children are fundamental to sound planning for those who have special needs.

This general Guide and the specific ones to follow are directed chiefly to persons in voluntary or official agencies or community organizations whose decisions singly or jointly determine the extent, coverage, content, and operation of community services to children, particularly children who are handicapped. Doctors, nurses, educators, social workers, administrators, and many others have been earnest participants in the preparation

of the material, and from the wealth of their experience this Guide has been produced. A great deal of concrete help was received from the staffs of state and territorial health departments and the Children's Bureau, and from members of the American Academy of Pediatrics' Committee on Mentally and Physically Handicapped Children, and the Association of State Maternal and Child Health and Crippled Children's Directors. Particular credit should go to Dr. Louis Spekter, who chaired the Advisory Group from beginning to end.

The Guides in this series are not statements of inflexible standards. They will serve their intended function only where they are adapted to fit specific community needs and situations.

Samuel M. Wishik, M.D.
Chairman, Committee on Child Health
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Section I:

CONCEPTS AND FACTS ABOUT HANDICAPPED CHILDREN

Who They Are

Most children grow and develop according to rates and patterns which, though personal for each, are considered to be within a "range of normality." These children are able to take advantage of available social and cultural opportunities and to become independent, adjusted, and contributing members of society. Limits of "normal" are not always clearly defined, and arbitrary judgment is sometimes necessary to decide whether or not a child falls within the expected range.

There are, however, in every community some children who deviate significantly from what is generally accepted as being average or "normal." In physical, mental, emotional, or social characteristics and growth they deviate to such an extent that they require extra help in order to develop to their best capacity. These are "handicapped children."

> The apparently robust 8-year-old who has had two epileptic seizures. Between attacks a casual observer would be unaware of his disability. There might be little to show how much he is upset or how worried his parents are about his future.
>
> The 3-year-old girl who cannot climb steps without becoming deeply cyanotic and short of breath because of a heart condition. Her handicap is evident to all and even her very life may be at stake.

The 16-year-old boy who cannot compete with his schoolmates in baseball, track, and other sports because of a severely paralyzed leg. He may need help in finding satisfying and socially acceptable ways of fitting in with his group.

The 3-year-old whose peculiar speech and difficult behavior are a source of concern to his parents. It is becoming evident that he cannot hear well and that his protracted winter colds and running ears need attention.

The 14-year-old girl whose cleft lip was repaired when she was a few weeks old. The scar below her nose was of little concern to her while she was young; now that she is an adolescent, it is a threat to her social and emotional adjustment.

A child is considered to be handicapped if he cannot within limits play, learn, work, or do the things other children of his age can do; if he is hindered in achieving his full physical, mental, and social potentialities. The initial disability may be very mild and hardly noticeable, but potentially handicapping; or it may seriously involve several areas of function with the probability of lifelong impairment.

The problem may appear to be primarily physical; or perhaps emotional or social. Regardless of the nature of the chief manifestations, physical, emotional, and social components are all factors at one time or another, and in varying degrees, in most handicapping conditions of childhood.

In this Guide, the term "handicapped children" will refer to the foregoing broad definition. For specific medical or administrative purposes, the meaning and scope of the term may need to be more specifically defined.

Numbers of Handicapped Children

Combined results of local surveys, state reports, special studies, and other isolated research projects offer a basis for

estimates on the number of handicapped children in the United States, but there are obvious limitations in the exactness of the data stated (SEE APPENDIX A). Advances in medical science and public health methods make estimates for future trends conjectural. On the one hand:

Case finding and earlier treatment are improving chances of simpler and more successful care (e.g., clubfoot).

Appreciation of the importance of good prenatal care and other preventive services is becoming more widespread.

Antibiotics and other new and effective drugs are playing their part in the elimination of many potentially handicapping conditions (osteomyelitis), and in the control of others (epilepsy).

On the other hand:

The total child population is increasing, so that the number of handicapped children may be expected to increase.

The causes of all the handicapping conditions are not known, and even where causes are known, preventive measures may not be available or widely applicable at the present time.

Among those conditions which are preventable, there is a lag between knowledge of preventive measures and their practice.

Modern medical care is saving the lives of more premature babies and of children with acute and chronic illnesses than ever before. Many of those saved may be left with residual crippling defects.

Thus, the size of the problem is not so much related to total numbers as to its continually changing pattern. As certain handicapping conditions are brought under control, others assume priority. Community programs should be adaptable to these shifting needs and emphases.

Difficulties to Be Faced

Because growth is a characteristic of childhood, all children face years of change and adjustment as they develop. In most families this process, with minor and temporary exceptions, is rewarding and relatively uneventful. The birth of a child with a defect or the discovery of a handicap, however, may initiate a series of disturbing events involving the child, his family, his friends and the community they live in. Feelings of blame or shame, misunderstanding and disappointment, may disorganize family relationships. Lack of services and facilities to help and heavy financial demands may increase the burden.

One of the chief problems faced by a handicapped child, his family, and the community is that of finding adequate resources. Like other children, those who are handicapped need medical aid, hospital facilities, education, and opportunities for gainful employment, but because of their varied and sometimes serious problems, many children with handicaps require additional special professional skill and attention. Few of the truly disabling conditions can be adequately cared for on a single doctor-patient basis.

The long-term nature of some phases of care and the high cost of treatment place further strain on family and professional resources. Medical evaluation and rehabilitation, guidance, special education, and vocational training are increasingly becoming community problems. It is moreover now widely accepted that the physical restoration of children with handicapping conditions is a special type of medical care problem not limited to the indigent.

Although many communities have excellent services and are carrying on worth-while and effective programs, there are others unable to make adequate provision for handicapped children. The following facts are illustrative:[8, 37]

Trained professional personnel are often lacking in

local areas and consultant services are sometimes unavailable to community programs.

The availability of needed hospital beds is proportionately greater for certain categories of handicapping conditions than for others.

Standards and quality of service in many institutions providing long-term care are not at a desirable level.

Many communities lack an adequate mechanism for coordinating the services given to handicapped children and for maintaining the necessary continuity of care.

Although the law recognizes the need for facilities to educate all children, those with handicapping conditions sufficiently severe to prevent them from attending regular school cannot obtain the education they need in many communities.

In isolated rural areas, distances are so great that services may not reach handicapped children.

The need for community-wide organization is evident. In those areas where a true shortage or poor quality of resources exists, many ways of improving local services may be found. Where resources are adequate, a review of better ways of using them is desirable.

Trends in the Organization of Services

The responsibility for seeing to it that children with handicapping or potentially handicapping conditions have adequate care rests upon the individuals and groups who make up the community. The past two decades have witnessed a rapid upsurge of interest in the problem so that many types of services have been and are being developed locally and nationally, under private and official sponsorship.

Voluntary programs

Much of the pioneer work has been and will continue to be

carried on by voluntary associations, both professional and nonprofessional. Current lists of these national organizations fill many pages. The activities and interests of these groups are broad, not only nationally but also within the states and local communities. They include:

Fund raising
Grants for research
Public education
Professional training
Setting standards for services and personnel
Building and equipping hospitals and centers
Direct services to patients
Provision of medical care services

Characteristic of the efforts of these voluntary groups has been the tendency to concern themselves with single types of handicapping conditions, as evidenced by such names as the following:

American Academy for Cerebral Palsy
American Association for Cleft Palate Rehabilitation
American Heart Association
American Speech and Hearing Association
Arthritis and Rheumatism Foundation
National Epilepsy League
National Foundation for Infantile Paralysis
National Society for the Prevention of Blindness
United Cerebral Palsy, Inc.

The activities of some voluntary groups have been more comprehensive, for example:

International Council for Exceptional Children
National Society for Crippled Children and Adults