

EDUCATING THE CHRONICALLY ILL CHILD

Susan B. Kleinberg



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To Ben and Allen and Leah
who have helped to keep me centered
within the love and community
of our family circle

Preface

This project was undertaken in order to attempt to bring together a number of lines of inquiry relating to the issues involved in educating the chronically ill child. Against the background of the developing child within the family, the following strands are interwoven: law and policy in regard to the educational rights of the chronically ill child; the psychosocial effects of illness; medical perspectives in diagnosing and treating the chronically ill child; and educational strategies and approaches. This book was written primarily for those who encounter the chronically ill child in an educational context—teachers of the homebound or hospitalized, special education teachers, regular teachers with a chronically ill child in the classroom, and hospital-based educational staff. It is my belief that a full awareness of these interdisciplinary issues is essential if one is to attempt to provide to chronically ill children coordinated educational programs that can fully meet their cognitive, social, and vocational needs.

A major impetus in writing this book has been my desire to share with others the model of coordinated interdisciplinary care of the chronically ill child that has been developing at Mt. Washington Pediatric Hospital. Change does not occur easily, especially when it threatens the roles and territory of health professionals. Often, these barriers act to build a wall around the child, with each professional peering into his or her own window, diagnosing the child and determining the child's needs from the professional's own perspective.

I have been active, with my colleagues at Mt. Washington Pediatric Hospital, in trying to tear down these walls. The task has been formidable and the process continuous, but well worth the effort. Again and again, our reward has been to see children improve medically, socially, and educationally and to maintain their gains after discharge.

Part I provides a historical background of programs designed for the education of the child with chronic illness, a discussion of the current legal perspective, and a review of normal growth and development as it pertains to psychosocial issues affecting the chronically ill child. Chapter 3 examines the overall effects of chronic illness on children and their families.

Part II clusters common diseases by category in terms of their common distinctive impacts upon the child's development, rather than in terms of medical diagnostic categories. This allows for a continuing focus on educational issues and strategies, reflecting the book's main emphasis on the application by educators of strategies appropriate for a given setting and age-graded population. Short medical summaries are provided for each disease, including likely age of onset, symptomatology, usual diagnostic and treatment procedures, effects of the illness and of its treatment on the child's behavior, prognosis, and any special considerations or restrictions, such as required bracing or dietary limitations. These medical summaries can serve as a handy reference tool for teachers, without requiring that they have an extensive medical background. Educational strategies and special techniques are described in detail in each chapter for preschoolers, school aged children, and adolescents in home, school, and hospital settings.

The choice of which disease entities to present and which to ignore has been a difficult one and one that is necessarily subjective. An attempt has been made to include those conditions most often encountered by educators that fall broadly under the definition of chronic illness. Burns and spinal cord injury have been included, since they are conditions that usually have an effect upon the child's educational and vocational needs. Cerebral palsy and mental retardation have been omitted, since these conditions are widely covered in other educational sources.

Part III focuses on the teacher's role as a member of an interdisciplinary team and provides guidelines for effective communication with health professionals. The need for teachers of the chronically ill child to recognize and deal with their own feelings and to act as advocates for chronically ill children is addressed. Suggestions are made for creating a supportive environment for the chronically ill child in school settings, along with ways to use the hospital as a learning environment.

Throughout the book, emphasis is placed upon the complex interplay of genetic, environmental, familial, and social factors as they affect the chronically ill child.

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The text could not have been readable without the tireless efforts of Laurie Grammer, child life secretary, who accomplished the herculean task of turning my scrawls into typed manuscript. The entire text was read with critical insight and edited by a very dedicated, caring person, whose vision of the whole and attention to detail combined to help make this handbook a reality—that person is Benjamin Kleinberg, my husband and partner.

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This book would not have been possible without the incredible spirit, courage, and stamina of chronically ill children and their families and the untiring dedication of their teachers and counselors.

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Chronic Illness: Theoretical Perspectives

OVERVIEW

Part I provides a discussion of two major theoretical dimensions involved in educating chronically ill children. Chapter 1 presents an examination of the policy issues involved in the delivery of services. Chapter 2 considers the child within the system and provides a theoretical model of psychosocial development. This dual perspective sets the stage for understanding the effects of chronic illness on the child and the family, explored in Chapter 3.

These issues form the basic framework for educating chronically ill children. Educational strategies need to be developed within the context of the environment, and the child's and family's unique needs. Without such a framework, there is the danger of developing strategies that are unrealistic, unworkable, and thus unused.

Chronic Illness: Policy Issues

OVERVIEW

The development of appropriate, comprehensive educational programming for the nation's chronically ill children is a formidable task, yet one that is essential from both a legal and an ethical perspective. Over the years, home/hospital programs designed to serve the needs of the physically handicapped seriously ill child have increased in both quantity and quality. Beginning with a few hospital schools on the wards of large, innovative children's hospitals and informal home visits made by regular classroom teachers, home/hospital teaching programs have evolved to take their rightful place in the continuum of special education services. Yet for the child with chronic illness, who may, after an initial period of disability, attend school sporadically, home/hospital services have yet to make significant inroads. This chapter will examine the availability of such home/hospital services around the country, the requirements for certification for teachers engaged in this kind of special education programming, and the laws relating to the education of the chronically ill child.

Before beginning this examination, however, it is essential that the population that will be discussed throughout this text be defined. Who is the chronically ill child? Is there a standard definition of chronic illness? Which conditions fall within this definition?

CHRONIC ILLNESS DEFINED

Chronic illness is not a single disease entity but rather an "umbrella" term (Travis, 1976). It is not equivalent to a long-standing physical or neurologic handicap, such as cerebral palsy, for these children can be either ill or well, independent of their handicap. It is a set of conditions that affects one or

more body organs and represents an active disease process. It may last many months or a lifetime. It may be secondary to an inherited disorder, such as hemophilia, or it may be acquired at birth or in early childhood or be the result of an acute illness or injury (e.g., seizures following closed head injury) (Myers, 1975).

Chronic illness may be life-threatening or relatively benign. It may leave the child permanently damaged, as in the scarring from burns, or may be resolved with little or no aftereffects or sequelae. In many cases, psychological effects may be present long after the disease process has been resolved.

Can chronic illness be defined by certain features common to all? The Commission on Chronic Illness in the United States (1957) defined the term as including all impairments or deviations from normal that have one or more of the following characteristics: are permanent; leave a residual disability; are caused by nonreversible pathologic alteration; require special training of the patient for rehabilitation; or may be expected to require a long period of supervision, observation, or care. Ake Mattsson (1972), who has researched chronic illness and its effects for many years, provides this definition: "Long term or chronic illness refers to a disorder with a protracted course which can be progressive and fatal, or associated with a relatively normal life-span despite impaired physical and mental functioning. Such a disease frequently shows periods of acute exacerbations requiring intensive medical attention" (p. 108). For the purposes of this book, chronic illness will include those conditions that usually require homebound or hospital instruction, such as burns; trauma from physical injuries that are long-standing, such as spinal cord injuries or closed head trauma; and conditions more classically defined as chronic illness, such as asthma, diabetes, cystic fibrosis, and cancer.

Acute Versus Chronic Illness

Children suffering from a short-term acute illness or a self-limiting physical disability such as the fracture of an extremity receive intense medical treatment over the course of their disorder. They often are absent from school during this time. Educational programs can be provided for these children on a short-term basis at home or in the hospital so that they can maintain their academic progress and return to the mainstream when their condition is fully resolved. Whenever children are seriously ill or are involved in an accident in which bodily injury results, developmental continuity is broken. Children must adapt to strange surroundings and undergo the trauma and stress related to the accident or illness and concomitant treatments. Often, the actual effects of the condition are less serious than the child's perceptions of them. With careful preparation and sensitive handling by parents and professionals, permanent damaging physical or psychological effects of short-

term accidents or illness can be minimal. Children and their families can "get on with" their lives and return to their normal patterns at home, at school, and in the community.

This is often not the case for children with chronic illness. For most children and their families, the condition does not get better and disappear. Even with good control and years of remission, the threat of a recurrent crisis is everpresent. Children with chronic illness have long-term educational, social, and emotional needs that must be addressed. These children are not confined to beds or hospitals except for occasional flare-ups of their disease. They attend local schools and are involved in after-school community activities to the extent that their limitations permit them. They are at home, in the community, and in the schools for a much more significant proportion of their lives than they are in hospitals.

Yet these children have frequent bouts with acute stages of their illness and are often hospitalized or homebound for significant numbers of days during their school career. For example, the asthmatic child may have near normal attendance during the bulk of the school year but spend most of the spring and early fall months in the hospital or at home due to increased allergic conditions in the environment. The child with rheumatoid arthritis may miss a number of school days during the cold, damp months in northern climates, while having near perfect attendance on warm dry days. Clearly, the inconsistent and unexpected nature of their absences is a factor to reckon with in planning for their educational continuity.

CHRONIC ILLNESS: SCOPE OF THE PROBLEM

It is impossible to state with certainty the number of chronically ill children in the United States today. Definitions vary, and statistical computations are often made for particular disease entities or by specific localities rather than nationally. Infants are particularly vulnerable and often die in the early weeks of a potentially life-long chronic illness, although medical technology has made remarkable progress in this area. Infants born with serious heart defects or meningomyelocele were often unable to survive the neonatal period until the last few decades. Neonatal surgical techniques and modern technology have changed this picture dramatically. J.P. Reichmeister (1980), a Maryland physician specializing in meningomyelocele, estimated that 30 years ago 90 percent of those children born with the condition died in infancy, whereas today 90 percent are saved through a series of medical interventions.

Unfortunately, many children thus saved remain impaired to one degree or another and face a lifetime of coping with the limitations imposed upon them by their condition. There is general agreement in the literature that 7 to 10 percent of all children suffer from some form of chronic illness (Mattsson,