

Chapter 16

Case Studies of Chronically Ill Children: Implications for Education Professionals

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ABSTRACT

Medical advances have increased the number of children who have survived and are now living with chronic medical conditions (Irwin & Elam, 2011; Singer 2012). Diseases and conditions that as recently as a decade ago were considered fatal or completely debilitating are now increasingly treated as chronic conditions. Among these are several types of cancer, HIV/AIDS, respiratory illnesses, and severe epilepsy. Increasingly, students with severe chronic conditions are educated in public schools instead of home or hospital settings. The purpose of this chapter is to present case studies of real children and families that will allow educators and others a personal glimpse into the lives of children with chronic illness and their families. Suggestions for analyzing the case studies are provided that will help teachers, administrators, and teacher educators to examine the complex issues surrounding the educational needs of children with chronic illnesses.

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CASE STUDIES OF CHRONICALLY ILL CHILDREN: IMPLICATIONS FOR EDUCATION PROFESSIONALS

The purpose of this chapter is to provide a brief historical overview of how children with chronic illnesses and their families have been served by educators, to track the development and application of legislation that pertains to chronically ill children, and to apply these ideas to four case studies of children with chronic illness. The treatment of children with chronic illnesses often mirrors that of children with other severe disabilities such as intellectual disabilities or autism. Early efforts at supporting these children generally took place in institutional settings where safety and medical treatment were the primary concerns. Additionally, families began to express interest in having their children educated in more inclusive settings. School districts, however, resisted these efforts to include students with disabilities and refused to accept them into public schools.

As parents began to advocate and as legislation such as IDEA and later NCLB were enacted, children with chronic illness have been included more in the regular education setting. This chapter will describe the push and pull between those who believe that full inclusion is the best setting for students with chronic illness and those who believe that more restrictive settings are preferable. As the four case studies included here show, children with chronic illness and their families need to learn to adapt to serious medical conditions while attempting to live as normal a life as possible. Through no small measure of drive and resiliency, the children and their families show that it is possible to manage chronic illness, maintain a sense of humor, and pursue educational, social, and career goals. Readers of these case studies will be asked to apply information from the opening remarks in the chapter and their own experience through a series of questions.

Medical advances have increased the number of children who have survived and are now living with chronic medical conditions (Irwin & Elam, 2011; Singer 2012). Diseases and conditions that as recently as a decade ago were considered fatal or completely debilitating are now increasingly treated as chronic conditions. Among these are several types of cancer, HIV/AIDS, respiratory illnesses, and severe epilepsy.

A Historical View of Legal Issues Pertaining to Students With Disabilities

Since the 1960s, United States federal legislation has focused on educating children with disabilities. These laws were the direct result of parents advocating for their children, and in some cases, suing school districts and state departments of education to force schools to accept their children with disabilities into public schools. In 1972, the Pennsylvania Association for Retarded Children (now the Pennsylvania ARC) sued the Commonwealth of Pennsylvania for allowing its school districts to exclude students with moderate to severe cognitive delays from participation in school. Parents were told that the school had no ability to serve their children and went so far as to tell parents that school districts were not responsible to teach children who did not have the capacity to learn. After mere hours of testimony, the Commonwealth of PA conceded it had compulsory attendance laws, and the PARC Consent Decree was issued requiring schools to admit and serve students with intellectual disabilities.

Following the PARC Consent Decree, parent groups across the United States pressured the federal government to mandate and fund special education as a basic right for all children with disabilities. In 1975, the Education of All Handicapped Children Act (EHA), also called Public Law 94-142, and later renamed the Individuals with Disabilities Education Act (IDEA), ensured that children and youth, ages birth through 21 with disabilities would have equal access to an education. Through this law, the

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