

## Chapter 29

# Educating Students with Chronic Illness: How the Old Service Model Fails

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### ABSTRACT

*Students with chronic illness have historically received an education via home and hospital instruction during their absences. This instruction is significantly inferior in both quality and quantity when compared with the educational experience of students able to attend school. This case study details the experiences of a middle school student in the mid-Atlantic Region of the United States whose chronic illness presented unique and multifaceted challenges that could not be met by her district's inflexible policies and disconnected resources. This case illuminates the need for schools to break away from the traditional administrative special education mold when responding to the challenges of educating frequently absent students with chronic illness. The educational Civil Rights of these students can be preserved, however, by utilizing affordable, available technology to minimize the impact of frequently missed classes, provide continuity of instruction and allow educational access regardless of a student's physical location during their absences from school.*

### INTRODUCTION

Nearly 31% of school-aged children in the United States suffer from some type of chronic health condition (McCabe & Shaw, 2008). This percentage has risen significantly in the past decade. Chronic illness is defined as a “medical condition of extended duration that creates impairment in adaptive behavior and socially defined roles” (McCabe & Shaw, 2008). Adaptive behavior includes communication, daily living, self-care, academic functioning, and motor behaviors. Socially defined roles include play, social

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interaction, family roles and schooling. Chronic illness can be as basic as exercise-induced asthma or as complex as an active HIV infection (Gortmaker & Sappenfeld, 1984). While the types of chronic illnesses may vary, they all negatively impact a student's attendance and performance in school. Over 45% of children with chronic illness report struggling with academic progress and nearly 60% regularly miss school (Lynch, Lewis, & Murphy, 1992). Children with chronic illnesses often push themselves to their limits in school and attend school despite feeling quite ill, when their "healthy" peers would have stayed home. This fact can have a negative effect on the academic performance of chronically ill students, as well. In addition, absences necessitated by chronic illness often have adverse consequences on peer relationships (Cook, Schaller, & Krischer, 1985). Further, when chronically-ill students do interact socially, they eventually recognize the differences between themselves and their healthy peers (Isaacs & McElroy, 1980). This can have deleterious consequences on their self-esteem.

To further complicate their existing challenges, many children present with more than one chronic illness, requiring teams of educators to think creatively about ways to meet the needs of these students within the federal legal framework. School districts in the US must comply with a range of prescriptive laws designed to ensure all students receive an appropriate education, including the Individuals with Disabilities Educational Improvement Act, Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act and the partially-repealed No Child Left Behind Act. Prior to 1973, there was no intersection of health and education because they truly existed in separate spheres; and even after four decades of intertwining these arenas, healthcare professionals and educators lack clear, collaborative guidelines governing the provision of an appropriate, inclusive education for children with chronic illness.

All these factors together create an even greater need for educators and administrators to adapt to this changing and evolving group. The needs of this growing population are significant placing a high premium on school districts to meet those needs; and yet, school districts are underfunded and ill-equipped to meet these challenges (Leachman & Mai, 2014). Some districts have gone so far as to reduce individualized education plan goals and remove students altogether from special education programs in an effort to meet the requirements of unfunded mandate within the constraints of their budgets. In order to save money, one district in Connecticut illegally changed students' individualized education plans without parental consent (DeNisco, 2013). A New York district denied students with disabilities the proper educational services in order to meet the budget needs of their district (Petrellese, 2013).

The purpose of this chapter is to present a case study and show how it relates to federal laws and schools. Specifically, the chapter will illustrate and identify universal challenges facing educators and administrators charged with providing an education to children with chronic illness and offer solutions that will prevent them from bankrupting their budgets and breaking the law.

## **BACKGROUND**

During the 2011-2012 academic school-year, one of the largest school districts in the US Mid-Atlantic region was grappling with how to resolve the legal and health issues presented by a newly-enrolled middle school student with multiple chronic illnesses. This case highlights the need to break away from the traditional administrative special education mold in order to tackle the exceptional challenges of preserving the educational Civil Rights of a student with a life-threatening chronic illness. This particular student and her family presented the District with unique and multifaceted challenges that seemed to stack higher and higher, dwarfing the shallow pool of resources designed to meet them.

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