

Chapter 20

School Counselors' Role in Working With Students Living With Chronic Illness

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ABSTRACT

Approximately 10-20 million children within the United States lives with a chronic illness. School counselors, by nature of their education and training, are in a prime position to work with and advocate for this population. Students with chronic illnesses struggle with reentry into the school system, as well as a myriad of obstacles related to social, emotional, academic, environmental, or familial factors. School counselors may use their positions within the school system to proactively ensure positive and proactive reentry for students with a chronic illness. The purpose of this chapter is to examine the academic obstacles of children living with a chronic illness. The examination includes discussion of the role of the school counselor to help navigate these obstacles. Finally, the end of the chapter briefly discusses possible areas of growth in knowledge regarding school counselors working with students with chronic illnesses.

INTRODUCTION

Approximately ten to twenty million children within the United States lives with a chronic illness (American Academy of Pediatrics, 2020). A variety of illnesses or disabilities fall within this category, but of importance is the use of the word 'chronic.' Chronic illness in children is any illness or disability that lasts longer than three months (American Academy of Pediatrics, 2020). Living with a chronic illness presents a number of obstacles for the child. Obstacles can take the form of environmental, social, familial, emotional, physical, or academic in nature (Hamlet et al., 2011). In essence, living with a chronic illness and the related obstacles may become a new reality for the child, as well as the systems in which the child is involved. Approximately one-third of children with chronic illness experience symptoms that create obstacles specifically related to academics (Hamlet et al., 2011; Kaffenberger, 2006).

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The complex nature of treating a child with a chronic illness creates difficulty (Kaffenberger, 2006). Treatment often includes multiple and frequent medical interventions and also lifestyle restrictions. Treatment difficulties can, therefore, increase struggles within the academic environment (Hamlet et al., 2011; Harden et al., 2020). School systems, medical systems, family systems, and environmental systems that could impact the student with chronic illness' daily functioning add to the complexity of working with this population. The focus of this particular chapter is to examine the academic obstacles of children living with a chronic illness. The examination includes the role of the school counselor to help navigate these obstacles. Finally, the end of the chapter discusses possible areas of growth in knowledge regarding **school counselors** working with students with a chronic illness.

SCHOOL REENTRY OBSTACLES FOR STUDENTS WITH CHRONIC ILLNESS

Thies and McAllister (2001) noted that within the academic setting, special education services tend to focus on students with developmental disabilities. Focusing on students with developmental disabilities leaves students with a chronic illness without academic services. Lack of special education systems for students with a chronic illness means that their health and educational needs within the school are not being met (Thies & McAllister, 2001). Lack of special education for students with a chronic illness also implies that teachers and staff within the school system may not have adequate skills, knowledge, or training to adequately assist students with chronic illness. Entire school systems should support students with chronic illnesses (Hamlet et al., 2011).

Students with a chronic illness find themselves stuck between two systems – medical and academic. Medical and school systems traditionally operate in two distinctly different modalities. Policies and philosophies, specifically, can be different within these two systems (Kaffenberger, 2006; Thies, 1999). For example, the medical system may focus on physical wellbeing of the student with a chronic illness, including medications, other invasive medical interventions, or mediation of symptoms, such as pain. School systems, on the other hand, may focus on the student with a chronic illness' schoolwork, **academic success**, and absences. School systems may have strict absence requirements prior to a student qualifying for home instruction or other flexible learning (Kaffenberger, 2006). Waiting until a student with a chronic illness misses the required number of days per the school system could potentially leave the student far behind their peers and unable to adjust to accommodations necessary for **academic success**. School systems should be proactive in having plans and procedures in place to specifically address students with a chronic illness. Unsupportive school system policies are one of the **barriers** found to be associated with **reentry** into the school system (Kaffenberger, 2006).

The priority of which system (school or medical) becomes the focus is dependent on whether the student is currently exhibiting physical implications (poor health) due to the chronic illness or not. If the student is actively, acutely ill (exhibiting medical symptoms of acute poor health), the medical system may take priority. If the student is medically stable (not acutely ill), learning and the school system may become the primary focus. The binary nature of these competing systems creates difficulty for the student with a chronic illness: the two systems may not communicate or work collaboratively with each other (Hamlet et al., 2011; Harden et al., 2020; Kaffenberger, 2006; Thies, 1999).

A school counselor may receive information related to the necessity of flexible learning through the family system, the student with a chronic illness themselves, or via school administrators or classroom teachers. Once a school counselor is made aware of the nature of the student with a chronic illness'

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