

Chapter 65

Parents as Advocates for Children with IBD at School

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ABSTRACT

Inflammatory Bowel Disease (IBD) is an “invisible” chronic illness, which is largely internal without significant observable external symptoms. Children with IBD experience painful and fluctuating physical symptoms caused by intestinal inflammation, as well as side effects from the medications. As a result, they necessitate special accommodations while they are in school. The Quebec Education Act (2010) stipulates that adequate services for a diverse student population must be provided. A case study conducted by Gordon (2013) with five families that participated in individual, semi-structured interviews revealed that families with a child with IBD functioned relatively well. These outcomes are contrary to the literature on families of children with disabilities. However, in Quebec public schools, parents and their children experienced teachers who lacked awareness of IBD and who provided insufficient classroom support. Hence, parents-(predominantly mothers) played an integral role in advocating for necessary accommodations on their child’s behalf. This chapter will present the parents’ school experiences and conclude with practical recommendations for teachers and families.

INTRODUCTION

In Canada, children with a variety of physical, psychological, and behavioral disorders have the choice of being enrolled in public or private school and they may require some form of special accommodations. Children with Inflammatory Bowel Disease (IBD) are an example of students with specific health needs who are placed in general education classrooms. Most children with IBD require special accommodations while they are in school because of the fluctuating physical symptoms of their disease and the side effects from their medications (Mackner, Sisson, & Crandall, 2004).

The responsibility of providing adequate accommodations for a diverse student population rests with school administrators and teachers, and sometimes the service delivery in classrooms is inadequate for children with IBD (Gordon, 2012, 2004, 2013). It is interesting to note that although Canada has the

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highest reported rate of IBD in the world (Bernstein, Wajda, Svenson, MacKenzie, Koehoorn, Jackson, Fedorak, Israel, & Blanchard, 2006; Crohn's and Colitis Foundation of Canada 2008), there are few teachers who are knowledgeable about this incurable disease (Gordon 2012, 2004). One of the reasons for this lack of knowledge about IBD among educators may be because the major disease symptoms are not visible.

Parents are then left to assume the responsibility for educating their child's teachers about IBD and the underlying symptoms of the disease. Despite these efforts parents overwhelmingly report that teachers and school staff fail to adequately accommodate their sick child.

A qualitative case study was designed by Gordon (2013) to explore the Quebec school experiences of five parents of children with IBD. The purpose of this chapter is to discuss the important role that parents play in the educational lives of children with IBD. The chapter begins with a description of IBD followed by a historical overview of the evolution of the educational system in North America for children with disabilities. The chapter concludes with the presentation of a case study by Gordon (2013) that explored the school experiences of parents of children with IBD. The study outcomes are discussed and recommendations for educators, teachers and families are explored.

As discussed in detail in Chapter 1, IBD is an umbrella term that encompasses mainly two chronic diseases, Crohn's and ulcerative colitis. What differentiates the two is simply the location at which the painful intestinal inflammation is occurring. Currently the only methods for managing this chronic disease is by way of surgery or steroidal medication since there is no known cure nor clear understanding of how one gets the disease.

Historical Overview of Parental Advocacy in Education

In North America, school programs began for children with disabilities in the 1950s and 1960s, almost all of them were conducted in special schools or centres for youth with disabilities. It was then believed that the students were better able to learn with others of "their own kind." (Crawford, 2005; Porter, 2008). Most educators also thought that it would be virtually impossible to educate children with mental and physical disabilities in general education classrooms. However, during the 1970s and 1980s, a major thrust toward integrating children with disabilities into school programs with typically developing children occurred (Reynolds & Birch, 1982; Schifani, Anderson, & Odle, 1980). This change was an outgrowth of a number of important social, political, and educational factors such as the overall trend towards community integration. Additionally, the work of parents and advocates to obtain access to regular public schools and the research that identified the learning potential of children with disabilities placed in general education classrooms helped to bring about changes. Moreover, the demonstration projects that illustrated methods and results of integration efforts (Curtin & Clarke, 2005; Turnbull & Turnbull, 2001; UNESCO, 1994; UNESCO, 1989) also bolstered the cause.

Now, throughout North America, policies are in place to provide all students with disabilities the opportunity to be educated "in the least restrictive environment." For the most part, this means that "to the maximum extent appropriate, exceptional children should be educated with non-exceptional children" (Schifani, Anderson, & Odle, 1980, p. 8). In 1979, the Québec policy stated that children with disabilities should be educated with non-disabled children in the "most normal" setting possible (Ministère de l'Éducation du Québec, 1979).

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