Chapter 1

The School Experiences of Children with Inflammatory Bowel Disease

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ABSTRACT

Are the special needs of students with a chronic disease such as inflammatory bowel disease (IBD) being met at school? A qualitative case study conducted by Gordon (2013) with six youth with IBD between seven to 18 years of age were interviewed. Individual interviews were performed to explore their perceptions of their school experiences. Research conducted from the student’s perspective is sparse and this study aimed to hear the student’s school stories first hand. The chapter reveals the findings from the study and provides an overview of the Quebec school system and the evolution of educational reforms that were amended for the purpose of accommodating students with special needs. The value in seeking students’ points of view regarding their education is also discussed. The chapter concludes with recommendations made by students for educators teaching in inclusive classroom settings.

INTRODUCTION

Canada is purported to provide equal opportunities to school access for all children. However, access alone does not guarantee equity in student school experiences (Dunleavy, 2007). A diverse student population undoubtedly calls for diversity in the educational practices and delivery of services for students. As such, a monolithic structure is unable to satisfy the needs of every learner and the challenge of education then becomes how to create classrooms, schools, and school systems that achieve equal opportunity and positive outcomes for all students. One way to overcome the challenges of inequity among diverse student populations is to engage in more extensive conversations with students and include their points of view into the school structure. Hearing what students have to say and integrating their perspectives into their schooling is a valuable way of moving Canadian inclusive education practices forward (Dunleavy).

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Currently, schools in the province of Quebec that are operating under the banner of inclusion should provide programs that meet the varying needs and interests of their diverse student populations (Banks, 2001; Lupart & Webber, 2002). However, there seems to be a disconnect between the concept of inclusive education and that which is actually practiced within schools and classrooms (Hutchinson, 2007). Therefore, one cannot claim the efficacy of inclusive schooling without hearing directly from the recipients and participants of this type of schooling.

As such, student’s input becomes vital to understanding if an inclusive system is in place and how affectively and/or successfully it is being implemented. Within the school context there is growing evidence that children do better personally, socially, and academically when they are encouraged to take ownership of their learning (Bearne, 2002; Cox, 2000; Weare, 2000). It is for these reasons that students’ perspectives are critical to understanding the current inclusive education system in Canada.

Students represent hidden voices that, if listened to, may assist in making schools and classrooms more inclusive (Ainscow, Farrell, Tweddle, & Malki, 1999). Failure to engage more deeply with students in conversations about their learning increases the risk of student disengagement from the experience of school (Dunleavy, 2008).

This chapter will explore the reasons for valuing students’ perspectives when discussing inclusive education. Listening to what students have to say about their educational experiences is one way to determine the best methods required to support their needs and to assist schools to develop inclusive practices. In this chapter, findings from a qualitative study conducted by Gordon (2013) that examined the school experiences of six children with inflammatory bowel disease (IBD) between the ages of 7 to 18 will be discussed. The study employed one-on-one semi structured interviews with the six children that had IBD and who also attended inclusive classrooms in the province of Québec. The purpose was to hear the six children’s stories regarding their experiences and their perceptions of their inclusive classrooms. Through this examination, an understanding of their social, psychological, and physical wellbeing at school emerged.

For these reasons, children’s perspectives should be considered when making educational decisions related to the implementation of curricula, school organization, assessment of learning outcomes, and practices that enable each student (with or without a disability) to fully participate in an inclusive school environment (Corbett, 2001; Sebba & Sachdev, 1997).

The background literature on inclusive education has so far, focused on research aimed at examining the beliefs, attitudes, and values from teachers’, parents’, and administrators’ perspectives (Bearne, 2002; Cox, 2000; Weare, 2000). Therefore, there is limited research available on inclusive policies and practices from the students’ perspective and this is the reasoning a study was conducted by Gordon (2013) to investigate the inclusive school experiences of children with IBD.

**WHAT IS INFLAMMATORY BOWEL DISEASE?**

In order to comprehend the school experiences of children with IBD, a basic understanding of the chronic disease is needed. Inflammatory bowel disease is categorized by two main diseases, namely, Crohn’s disease and ulcerative colitis. These two diseases, though similar in nature, differ in the physical location in which they occur. Both diseases are characterized by chronic recurrent inflammation of intestinal tissue, evolving in periods of relapse and remission. However, Crohn’s disease can affect any part of the gastrointestinal tract, from the mouth to the anus. Patches of inflammation occur, with