

School Experiences of Individuals with Down syndrome:  
Issues Surrounding Inclusion

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### Abstract

Down syndrome is the most common genetic disorder affecting individuals today. Since the 1970s, individuals with Down syndrome have been integrated into regular classroom settings; yet, little is known about how effectively efforts to apply the inclusion model are supporting this unique population of students. The voices of those potentially affected are also largely absent from what literature does exist, indicating a need to explore the school experiences of students with Down syndrome, in their own words. The purpose of this study was to offer this population of students, and their families, the chance to share their thoughts and memories of their school experiences in order to gain insight into how well the inclusion model has supported their unique social and academic needs. A qualitative approach was chosen in order to gain a more in-depth look into these experiences, and to recognize and value voices that are not often heard.

Participants in this study were four young adults with Down syndrome (one male and three females ranging in age from 20 to 32) and five parents. All student participants grew up and attended school in the same rural town in Nova Scotia (one student participant moved to said town in late elementary school). A qualitative methodology was utilized, and as such, each participant took part in a semi-structured interview in which they were asked to share their experiences of attending school (for student participants) and of watching and supporting their child throughout school (for parent participants). Thematic analysis was used to identify emerging themes in the data.

Participant data was divided into two groups, Parents and Students. Primary themes that were identified from the Parent data were: 1) School; 2) Parenting a student with Down syndrome; 3) Extra-curricular activities; 4) Friendship; 5) Bullying; and 6) Speech difficulties.

Primary themes identified from the student data were: 1) School; 2) Down syndrome; 3) Friendships; 4) Bullying/teasing; and 5) Extra-curricular activities. There were several sub-categories that emerged from each major theme. These themes provide a rich, detailed insight into the positive and negative experiences of students with Down syndrome and their parents as they navigated the school system.

## Table of Contents

<b>Chapter I. Introduction</b>	<b>7</b>
Introduction	7
Human Rights	7
Academic Advantage	8
Social Advantage	9
Summary	11
Down Syndrome	11
Historical Background	11
Prenatal Screening	12
Associated Health Problems	13
Prevalence	14
School Experiences	15
Bullying	15
Social Competence	15
Summary	18
 <b>Chapter II. Methodology</b>	 <b>20</b>
Purpose of the Study	20
Theoretical Framework	20
Reliability and Validity	21
Methods	22
Participants	22
Data Collection	23
Data Analysis	24
 <b>Chapter III. Findings and Discussion</b>	 <b>26</b>
Findings and Discussion: Parent Data	26
School	26
Teacher Relationships	26
Academics	28
Inclusion	30
Teacher Assistants	31
Parenting A Student With Down syndrome	32
Positives	32
Challenges	33
Down syndrome Questions And Discussions	34
How to Cope	35
How Schools Can Help	36
Extra-curricular Activities	38
School-based	38
Outside Agency/Organizations	40
Friendship	41
Naturally Formed Friendships	41
Friendship Groups/Programs	41

Interactive Settings	42
Bullying/Teasing	43
Speech Difficulties	44
Findings and Discussion: Student Data	46
School	46
Academics	46
Teacher Relationships	47
Down syndrome	47
Friendships	48
Naturally Formed Friendships	48
Friendship Groups/Programs	48
Interactive Settings	49
Bullying/Teasing	49
Verbal Abuse	49
Physical Abuse	50
Impact	51
Extra-curricular Activities	52
Summary	52
Conclusions and Recommendations for Future Research	57
Limitations of the Current Study	59
References	61
Appendices	68
Invitation to Participate (Student Participant)	68
Invitation to Participate (Parent/Guardian Participant)	70
Consent Form	72
Demographic Questionnaire	74
Interview Protocol (Student Participant)	76
Interview Protocol (Parent/Guardian Participant)	78
Debriefing Form	80

## CHAPTER I

### **Introduction**

In recent years, the issue of educational equity has been at the forefront of environmental and curriculum design in schools (McAllister & Hadjri, 2013). The inclusion of special needs students into mainstream schools is now generally perceived as an important component of working toward this concept of educational equity by providing equal opportunities for all students to learn in optimal environments (McAllister & Hadjri, 2013; De Valenzuela, Copeland, Qi, & Park, 2006). The push towards inclusion is driven by the idea that inclusion of special needs students is ethically correct from a human rights standpoint, and also that it is beneficial to these students in terms of greater exposure to academic and social advantages (Curtin & Clarke, 2006). For students with Down syndrome, a chromosomal condition characterized by distinctive physical features, as well as numerous medical problems and intellectual disabilities (Roizen & Patterson, 2003), the issue of inclusion may present a unique set of opportunities and challenges.

#### **Human rights.**

In Canada, up until the mid-1970's, many school boards were within their rights to exclude students with disabilities who were unable to meet the outcomes of the general classroom curriculum (Szechtman, 2006). This policy began to change as many countries re-examined their attitudes toward students with disabilities. In the United States, the Education for All Handicapped Children Act was passed in 1975, and was followed by the Individuals with Disabilities Education Act (IDEA), first passed in 1990, and renewed in 1997 and 2004 (Idol, 2006). The United Nations Convention of the Rights of Children in 1989 (United Nations, 1989), and the Salamanca Statement on Principles, Policy, and Practice in Special Needs Education in 1994 (United Nations Education Scientific and Cultural Organization, 1994) deemed inclusion in

mainstream school as a basic human right for all children (Curtin & Clarke, 2006). The Salamanca agreement has been particularly influential. Signed by 92 different nations, including Canada, it declares that inclusion is not only a right, but a matter of social justice (McAllister & Hadjri, 2013). In the UK, the Education Act in 1981 and 1996, as well as the Special Education Needs and Disability Act in 2001 and the Education and Inspections Act in 2006, pushed for inclusion of students with disabilities in the regular classroom, provided inclusion is in accordance with parental wishes, suitable for the student's needs, and not detrimental to the education of other students (Turner, Alborz, & Gayle, 2008). In Canada, the United Nations Convention on the Rights of Persons with Disabilities was adopted in 2006 and ratified in 2010, stating that persons with disabilities are entitled to full inclusion in educational settings (Bennett & Gallagher, 2013). This international trend of inclusion-based advocacy is strongly grounded in the idea that education is a basic human right that should be provided for all. Section 15 of the Canadian Charter of Rights and Freedoms also clearly indicates that every individual in Canada, regardless of race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability, is to be considered equal, and cannot be denied any opportunities available to other members of society.

#### **Academic advantage.**

Alton (1998) points out that there is a much wider range of development in students with Down syndrome than with their typically developing peers. This can make it difficult to generalize the academic benefits of attending mainstream schools. In a longitudinal study aimed at finding predictors of academic achievement in students with Down syndrome, Turner, Alborz, and Gayle (2008) found that the severity of intellectual impairment in their participants was by far the biggest predictor of academic achievement. That said, they also found that attending a



mainstream school was a modest predictor of greater academic success at three different stages of the students' school careers, as measured by the Academic Attainments Index, a 58-item battery measuring reading, writing, and mathematics ability. Teachers need to consider however, that children with Down syndrome generally develop skills at a slower rate than that of their typically developing peers, meaning that they arrive at different learning stages later and stay there longer, so the gap in learning widens with age and it can become more difficult to accommodate students with Down syndrome and other disabilities as they move into secondary school (Alton, 1998; Curtin & Clarke, 2005). In addition, teachers' attitudes towards inclusion tend to vary. Interestingly, teachers with more experience tend to view inclusion more negatively. This may be due to having received their teacher training in a time when inclusion was not the norm in schools (MacFarlane & Woolfson, 2013). Avramidis, Bayliss, and Burden (1999) found that younger teachers held more positive attitudes towards inclusion, but also had lower perceived competence for dealing with more severe needs. Research conducted by the Special Education Implementation Review Committee in Nova Scotia (2001) found that teachers had mixed views on progress of inclusive schooling, although teachers taking part in a focus group summed up the general consensus by stating, "No one wants to go back. Inclusion is better" (p. 98). The majority of these teachers felt that more funding and resources were needed. Some other suggestions to improve inclusive education included: increased programming and services, more opportunities for professional development, additional in-class support, increased inclusive school activities and learning experiences, enhancing teacher skills in making adaptations, clarifying the definition of inclusion, increased peer support, and improving pre-service education (Special Education Implementation Review Committee, 2001).

**Social advantage.**

Few would now argue that the inclusion movement is not a morally sound change to education. There is also some evidence to indicate that there are academic advantages to attending mainstream schools (Turner, Alborz, & Gayle, 2008). Research indicates that positive social interaction is important in the development of perceived acceptance and self-esteem (Pitt, 2003). Attending a mainstream school theoretically exposes children with disabilities to a wider variety of experiences and interactions, and in turn, also exposes their non-disabled peers to different groups of people that they may have limited interaction with otherwise, hopefully promoting acceptance and understanding (McAllister & Hadjri, 2013; Curtin & Clarke, 2005). There is other evidence, however, to show that students with disabilities may be more likely to be bullied than typically developing peers (Flynt & Morton, 2004), and also may be ostracized or have few or no friends (Curtin & Clarke, 2005).

For students with Down syndrome, these social concerns have not yet been fully explored in the literature, making it unclear whether these students are, in fact, experiencing the supposed social advantages of the inclusion model. In particular, there is limited research exploring the degree to which these students experience bullying or negative peer interactions. Given the recent tragic cases of bullying in our schools that have received considerable media attention, it is important to understand how this type of behaviour is affecting all demographics of the student population. There is research detailing bullying of students with Asperger's syndrome (now included under the diagnosis of Autism Spectrum Disorder) (Carter, 2009; Garcia Biggs, Simpson, & Gaus, 2010), learning disabilities (Norwich & Kelly, 2004), intellectual disabilities (Sheard, Clegg, Standen, & Cromby, 2001), as well as Tourette syndrome and other chronic tic disorders (Zinner, Conelea, Glew, Woods, & Budman, 2012), but there is a major gap concerning students with Down syndrome. This is a population characterized by many of the

social, behavioural, cognitive, and academic difficulties that are common to these other disorders, but one that may also involve unique negative stereotypes and misconceptions, as well as being associated with numerous medical problems and distinctive physical features. All of these unique features of Down syndrome could possibly lead to very unique school experiences.

### **Summary.**

It is very important that the school experiences of students with Down syndrome be further investigated in order to determine the strengths and challenges of the inclusive education model in order to provide the best educational environment possible for these students. The current study aims to explore the personal school experiences of students with Down syndrome, and to provide them with a voice in the literature. As Rose (2003, p. 27) points out, “Researching *with*, rather than *on*, people with disabilities is an important distinction that must guide the motivations and actions of all who engage in the process.”

### **Down syndrome**

#### **Historical background.**

Down syndrome is the most common genetic disorder affecting children today (Davis, 2006). First described in 1866 as “the Mongolian type of idiot” (a description abandoned long ago due to its demeaning nature), John Langdon Down believed that the associated facial features of individuals with Down syndrome were evidence of shared ancestry among different ethnic groups (Down, 1866). He observed that people with Down syndrome, even those of Caucasian or African descent, bore striking similarities to people of Asian descent, leading him to ponder,

If these great racial divisions are fixed and definite, how comes it that disease is able to break down the barrier, and to simulate so closely the features of the members of another

division. I cannot but think that the observations which I have recorded, are indications that the differences in the races are not specific but variable. These examples... appear to me to furnish some arguments in favour of the unity of the human species. (Down, 1866, p. 3)

Much of the research in subsequent years revolved around determining intelligence levels and capabilities of individuals with Down syndrome (Pototsky & Grigg, 1942; Wallin, 1944), but the cause was still unknown. It was not until 1959 that Lejeune, Gautier, and Turpin (1959) linked Down syndrome to an extra copy of chromosome 21 (trisomy 21). This is caused by meiotic non-disjunction or from complications in postzygotic mitosis, wherein chromosomes fail to separate during cell division (Czarnetzki, Blin, & Pusch, 2003).

The overexpression of chromosome 21 manifests itself in very distinctive phenotypic features (Down, 1866; Czarnetzki, Blin, & Pusch, 2003; Roizen & Patterson, 2003), such as brachycephaly (flattening of the back of the skull), brachydactyly (shortened fingers and toes), broad hands, duodenal atresia (improper development of the small bowel), epicanthal folds (folds of skin above the eyes, common in those of Asian descent), fifth finger clinodactyly (curvature of the little finger), flat nasal bridge, hypotonia (low muscle tone), lax ligaments, intellectual disability, open mouth, short stature, and wide gap between the first and second toes (Roizen & Patterson, 2003).

### **Prenatal screening.**

There has been a great deal of controversy over the issue of prenatal screening for Down syndrome (Roizen & Patterson, 2003; Alderson, 2001; Bryant, Green, & Hewison, 2006), and this issue may have far-reaching implications in terms of the general social perception of Down syndrome. Julien-Reynier et al (1995) reported in a French study that of 280 prenatally identified

fetuses, 27% were aborted. Of the fetuses allowed to continue full term, 4% miscarried or were stillborn, 12% were given up for adoption, and a further 12% died in the first year of life largely due to medical problems or sudden infant death syndrome. What this means is that for every hundred fetuses with Down syndrome, roughly 39 will be aborted or put up for adoption, and about 16 will die as infants. Only about 45 will make it to their second year with their birth parents. In August, 2014, scientist and author Richards Dawkins weighed in on the issue via his Twitter account, stating that if a mother was aware that she was carrying a child with Down syndrome, she should “Abort it and try again. It would be immoral to bring it into the world if you have a choice”. There are many who take this very pragmatic, and perhaps very cold, view that fewer persons with Down syndrome equals less of a strain on society. Others would argue that this practice is simply propagating negative stereotypes by assuming that a child born with Down syndrome would be too difficult to care for or in some way unfit to live (Alderson, 2001). Interestingly, Dabrowska and Pisula (2010) found that parents of children with Down syndrome experience less parental stress than parents of children with Autism Spectrum Disorder, which begs the questions: if a similar prenatal screener existed for Autism Spectrum Disorder, would parents also be given the option to abort, and if so, where would the line be drawn in terms of which undesirable characteristics become grounds for terminating a pregnancy? Branding fetuses with Down syndrome as undesirable could help to further negative stigmas surrounding the disorder, stigmas that could follow these children through their schooling and their entire lives.

#### **Associated health problems.**

Persons born with Down syndrome face a number of related health issues, the most serious and one of the most common being congenital heart disease, which affects roughly half of children born with Down syndrome (Roizen & Patterson, 2003). Other common health

problems include hearing loss and vision problems, respectively affecting 38-78% and 80% of individuals with Down syndrome. Those with Down syndrome are also at risk for obesity, periodontal disease, gluten allergies, thyroid problems, arthritis, atlantoaxial subluxation (hypermobility and loosened tendons of the cervical spine, increasing the risk of spinal injury), diabetes mellitus, leukemia, obstructive sleep apnea, seizures, and dermatological problems (Roizen & Patterson, 2003). Due to advances in medical care, average life expectancy has increased dramatically in recent generations, from 25 years in 1983 to 49 years in 1997 (Yang, Rasmussen, & Friedman, 2002), however, for many these issues can still be debilitating. For young students, these medical issues could potentially limit the number and types of activities that they can take part in, which could in turn limit peer interaction and contribute to stigma.

### **Prevalence.**

Until more recent years, Down syndrome would have been extremely rare. A very interesting study conducted by Czarnetzki, Blin, and Pusch (2003) examined the prevalence of Down syndrome in ancient Europe. Remains from 7073 people who lived in Europe between around 3200 BC and AD 800 were examined for cranial features unique to individuals with Down syndrome, and only one matching specimen was found. Average life expectancy for the time period was roughly 20-30 years, which meant that most women gave birth at much earlier ages than today. One of the primary risk factors for Down syndrome is advanced maternal age, and for various reasons, families are currently having babies at much later ages than in previous generations. This means that while incidence of Down syndrome is likely on the rise, the number of terminated pregnancies is rising faster, and as a result the number of Down syndrome births has decreased from an estimated one in 700 in the nineteen-eighties to an estimated one in 1000 (Roizen & Patterson, 2003).

## **School Experiences**

### **Bullying.**

Children with Down syndrome face many obstacles when they reach school age.

Bullying is a huge concern in schools today, and it is very possible that many of the characteristics of students with Down syndrome could make them targets for peer victimization. Smith (2000) defines bullying as a habitual abuse of power characterized by repetitive verbal or physical aggression intended to hurt another person. The prevalence of this type of behaviour in schools is widespread, with an estimated 25% of elementary and high school students and a staggering 40% of middle school students reporting at least one incidence of bullying each week, (Flynt & Morton, 2004). Other estimates place the overall figure at approximately 30% of students experiencing frequent bullying (Nansel et al., 2001). What is unclear is the extent to which students with Down syndrome are experiencing bullying, and how they may be affected by bullying behaviours.

Flynt and Morton (2004) propose that bullies target students who are perceived as weaker than themselves, and that students with disabilities may be prime candidates. Many students with disabilities are characterized by lack of social awareness, motor skills deficits, and physical or health related limitations that may make them “easier marks” for bullies. The degree to which students with Down syndrome fit this profile may indicate that further study is warranted in this area.

### **Social competence.**

Socially, there is often a presumption that although children with Down syndrome experience cognitive difficulties, they have social skills similar to that of typically developing children. This is perhaps due to the stereotypical view of people with Down syndrome being very

outgoing, charming, and engaging (Cebula, Moore, & Wishart, 2010; Dykens, Shah, Sagun, Beck, & King, 2002), as opposed to students with other disabilities who may have deficits in social awareness. While it is true that individuals with Down syndrome score higher in social competence than other disorders such as Prader-Willi or Williams syndrome (Rosner, Hodapp, Fidler, Sagun, & Dykens, 2004), that is not to say that there are no deficits in social cognition skills when compared to their typically developing, chronologically same-age peers.

Research indicates that from a young age, there are subtle differences in the development of social cognition in children with Down syndrome relative to typically developing children. One of the earliest indicators is the delayed development of the ability to hold mutual gaze with parents or caregivers, and later in the first year of life, a delay in the ability to develop joint mutual attention (Cebula, Moore, & Wishart, 2010). After language begins to develop, Adamson, Bakeman, Deckner, and Ronski (2009) have found that children with Down syndrome are less likely to make personal requests or offer personal comments than typically developing children. Infants with Down syndrome also experience difficulty with social referencing, or using others' affective responses to situations to guide their own reactions, and these difficulties appear to extend into school age, with particular difficulties recognizing core facial expressions of emotion such as fear, surprise, and anger (Cebula, Moore, & Wishart, 2010). Collectively, these subtle differences in the development of social cognition skills may indicate a deficit in the understanding of social interactions or situations. Perhaps even more importantly, a higher risk for peer victimization may be more likely, as an inability to register anger in an aggressive peer could make it very difficult first to recognize, and then to avoid or diffuse escalating situations.

Hall and McGregor (2000) found that in elementary school, students with Down syndrome spend increasing amounts of time alone as they progress through school, are selected



less often as playmates, and speak less frequently than their typically developing peers. They also were observed not to make the typical shift to same-sex preferences for playmates as they progressed to upper elementary grades. The importance of social support in school cannot be overstated, as it can act as a protective agent against stress and crisis situations. Social support can be defined as “the perception one has of being cared for, valued, and included by others within a network of parents, teachers, peers, and community members” (Saylor & Leach, 2009, p. 71). Perceived social support has also been shown to be strongly tied to positive school engagement, but unfortunately, students with Down syndrome appear to struggle in building strong social bonds. A study of school aged children (n=204) with Down syndrome showed that despite showing relatively well developed social competence skills in previous research (Rosner, Hodapp, Fidler, Sagun, & Dykens, 2004), approximately one third of participants were reported to have no friends. While about half were reported to have two or more friends, the majority of this group reported seeing their friends only occasionally or about once a week. Students who scored higher on measures of independent functioning were more likely to have higher numbers of friends, while most who were reported as having one or no friends showed higher levels of disruptive and antisocial behaviour, self-absorption, and difficulty relating to others. These students were also less likely to become involved in leisure activities that would allow for more social interaction with their peers, with the majority having little or no involvement in team sports or activities, preferring solitary and predominantly sedentary pastimes (Oates, Bebbington, Bourke, Girdler, & Leonard, 2011).

There are other factors that may also make students with Down syndrome more likely to become victims of bullying than their typically developing peers. Down syndrome is characterized by very distinctive physical features that may make these students more vulnerable

to teasing and ridicule, and also a large number of health related difficulties. Combined with usually being short of stature and prone to obesity (Roizen & Patterson, 2003), bullies could easily view these students as easier targets for victimization.

While independent functioning skills are often well developed in children with Down syndrome, roughly 40% of students still require some degree of help with self-care activities, such as dressing, bathing, and grooming. Communication difficulties are also common, with over half of students with Down syndrome requiring help or supervision in communication with adults or peers (Leonard, Msall, Bower, Tremont, & Leonard, 2002). Kumin (1994) found that the vast majority of parents of children with Down syndrome (roughly 95%) reported that people outside of their immediate family had difficulty understanding their child's speech. Again, these difficulties with personal care and speech may be targeted by bullies as points of ridicule. Behaviourally, while children with Down syndrome do display fewer difficulties than children with some other disabilities, parents and teachers report more behaviour problems than seen in typically developing children, especially in the areas of attention, social withdrawal, stubbornness, and oppositionality (Coe et al, 1999; Lott & Dierssen, 2010). While severe psychiatric disorders are rare for individuals with Down syndrome, there is an increased risk of depression in adulthood when compared to the general population, which can lead to flat affect, apathy, and psycho-motor blunting (Lott & Dierssen, 2010). As many students with Down syndrome attend school until the age of twenty one, these depressive symptoms, along with other described behavioural problems, could very well lead to isolation, vulnerability to peer victimization, and intense personal suffering.

### **Summary**

First described in 1866, Down syndrome is the most common genetic disorder today. Caused by an extra copy of chromosome 21, it is characterized by distinctive physical features, intellectual disabilities, and numerous associated health problems. Down syndrome affects roughly one in 1000 children today, although rates may be falling due to widespread (and controversial) prenatal screening practices. Research suggests that these children may face a unique set of challenges during their school years, including an increased risk of peer victimization, and difficulties with social competence.

## CHAPTER II: Methodology

### Purpose of the Study

There is a large body of research that currently focuses on the issue of inclusion in schools, however, one must consider that this term refers to a large and diverse group of individuals with many different academic, social, and cognitive abilities, and that a blanket policy may not result in appropriate programming for such a wide range of needs. Students with Down syndrome in particular are underrepresented in the current literature in respect to their experiences in school. This study aims to give a voice to this population (and their families) to more fully explore the positive and negative experiences of students with Down syndrome in schools today.

### Theoretical Framework

In seeking personal insights into school experiences, a qualitative approach was chosen. While quantitative studies can yield very specific data about a variety of topics, qualitative research methods allow for much more elaboration and expression on the part of the participants. This allows for more detailed insight into individual experiences and provides “complex textual descriptions...about the ‘human’ side of an issue” (Mack, Woodsong, MacQueen, Guest, & Namey, 2005, p. 1). Branthwaite and Patterson (2011) point out that the interactive nature of interviews also allows for a shared understanding between researchers and participants. These qualities of qualitative research are directly in line with Rose’s (2003) notion of “researching *with*, rather than on, people with disabilities” (p. 27), and provide a population that is underrepresented in the current literature the opportunity to share their experiences in their own words. This qualitative study employed an exploratory approach, and as such, no specific hypotheses were made. Rather, it intended to explore the perceptions and experiences of these

students and parents in their own words, develop ideas for further research questions and begin to develop theoretical understanding of the particular positive and negative experiences of students with Down syndrome in school. Through a process known as thematic analysis, the study aims to identify, analyze, and report themes or patterns that the researchers identified from the data (Kisely & Kendall, 2011). Data will be carefully scrutinized over multiple readings to identify primary themes and subsequent sub-categories that are common among participants and that allow detailed insight into lived experiences.

### **Reliability and Validity**

The concepts of reliability and validity are central to the design of any quantitative research project. These concepts essentially ensure that data is collected in a manner that can be duplicated by peers, and that the data collected actually reflects what the researcher intended to be measured. While there are several key differences between quantitative and qualitative research, there are very similar concepts at the heart of establishing the trustworthiness of the data (Kisely & Kendall, 2011).

Quantitative research takes a hypothetical-deductive approach, by forming initial hypotheses, and then using objective methods to collect broad data to test said hypotheses. In contrast, qualitative research takes a much more inductive approach, by gathering a great deal of detailed information about a specific phenomenon or experience, and “allowing meaning to emerge from the data” (Kisely & Kendall, 2011). Essentially, quantitative research strives for maximum *breadth* in its results, or the ability to generalize or apply the findings to the population at large. Qualitative research is more interested in *depth*, or gaining a richer understanding of a very particular phenomenon, and building a larger knowledge base of the topic (Thomas & Magilvy, 2011).

These two very different approaches are, however, very similar in that researchers using either method must establish confidence in their results (Thomas & Magilvy, 2011). In qualitative research, the equivalent of reliability and validity would be qualitative rigor, which refers to establishing trustworthiness. Thomas and Magilvy (2011) point out four different components of trustworthiness that apply to qualitative studies: (a) truth-value (credibility); (b) applicability (transferability); consistency (dependability); and (d) neutrality (confirmability). A qualitative study is considered credible when the themes and experiences described allow others to recognize those same experiences in their own lives (Krefting, 1991). This is achieved by careful analysis of individual transcripts to tease out the common threads that exist across participants. A study is also said to be transferable when the results can be applied to other subjects or contexts. This is achieved by detailed and dense descriptions of the population that the study focuses on, complete with demographic and geographic details. Dependability refers to outlining a clear, step-by-step process of the entire research project, such that another researcher can duplicate the study. Lastly, confirmability occurs when the study has managed to establish credibility, transferability, and dependability. This also involves actively practicing reflective study, in which the researcher pays careful attention to the influence that personal attitudes and biases may have on the direction of the research, and the data analysis (Thomas & Magilvy, 2011).

## **Methods**

### **Participants.**

After receiving ethics clearance from the institution's Research Ethics Board, participants were recruited from an organization that provides employment, day programs, and housing for individuals with intellectual and developmental disabilities. The director of the organization was

consulted regarding the proposed research project, and potential candidates were contacted by the director to determine interest in participating. Potential candidates were defined as adolescents or young adults with Down syndrome who were either currently attending school or had graduated in the last ten years. Parents or guardians of the participants were also invited to be interviewed in order to gain another perspective. Four families responded to indicate interest in participating, and were contacted to discuss the study further, gain informed consent, and arrange interviews. Participants included a 20 year old female and her mother, a 24 year old male and his mother, a 32 year old female and her mother, and a 32 year old female and her mother and father.

#### **Data collection.**

After being contacted by eligible volunteers, interviews were scheduled at the participants' convenience. Prior to their interview, the purpose and procedure of the research was explained verbally to both parents and students, and then parents and students were also given an Invitation to Participate (see Appendices A and B) and read (or were read) and signed a consent form (see Appendix C). Parents/Guardians then completed a short demographic survey consisting of questions related to their child's educational background (see Appendix D). Participants were seated in a private room and a digital audio recorder was activated. Interviews were conducted using a semi-structured format consisting of several broad questions that could then be elaborated on in an effort to glean more detailed information (see Appendix E for Student Interview, Appendix F for Parent Interview). Interviews were conducted by the student researcher. Great care was taken by the interviewer to maintain a relaxed and comfortable atmosphere where participants could feel free to candidly discuss their experiences without fear of judgment. Questions were initially broad in nature before moving on to prompts and follow-

up questions in an attempt to elicit more detailed responses. For example, an initial question may have asked a participant to talk about his or her general feelings towards school, and additional probes may have asked for particular details about the participant's positive and negative school experiences. For student interviews, great care was taken to avoid leading questions or implying desirable responses. The length of interviews varied depending on participants' particular experiences and willingness to elaborate on responses, ranging from 14:20 to 41:30 in length for parents, and 10:22 to 20:54 for students. Interviews were ended when the student researcher deemed that no new pertinent information was being brought to light. The audio files (and subsequent transcripts) were saved under pseudonyms in order to protect participants' identities. Immediately following the interview, participants were given an oral and written debriefing (see Appendix F) detailing the purpose of the study and containing contact information for the researchers. Transcriptions of interviews were uploaded into NVivo, a program that allows researchers to organize and code data into different nodes and sub-nodes.

### **Data analysis.**

All interviews were transcribed verbatim, including non-verbal cues, such as pauses or sighs. All data was saved on a password-protected computer, and audio files were permanently deleted immediately following the successful defense of this thesis. The primary researcher and supervisor carefully read the first few interviews in order to begin coding. Notes were compared to establish inter-rater reliability. Initially, codes were very specific and numerous, as any mention of school experiences was included. As themes were identified, these initial codes were then grouped under broader headings.

The data then began to be coded using NVivo software. Interview transcripts were uploaded into NVivo and broad themes were entered as Primary Themes (i.e., "nodes"), which in



turn were then broken down into sub-categories. As each transcript was carefully read multiple times, and relevant sections were entered into their appropriate categories, the software compiled data based on how often and by how many participants each theme was discussed. It is hoped that participants' responses will allow a broader understanding of the issues that these young men and women face in the course of their school careers.

### **CHAPTER III: Findings and Discussion**

The purpose of this study was to gain in-depth insight into the lived experience of individuals with Down syndrome and their families as they navigated through the school system. By employing a qualitative research method and utilizing thematic analysis, personal accounts were carefully examined in order to identify significant and shared themes that arose from the data. This chapter is intended to present the findings in rich detail, and allow a population that may be underrepresented in the current body of literature the opportunity to share their lived experiences in their own powerful and compelling voices. A summary and conclusion of the research will follow, along with limitations of the current study and possibilities for future research.

#### **Findings and Discussion - Parent Data**

Participant data was divided into two groups, Parents and Students, which will each be discussed in turn. Primary themes that were identified from the Parent data were: 1) School; 2) Parenting a child with Down syndrome; 3) Extra-curricular activities; 4) Friendship; 5) Bullying; and 6) Speech difficulties. There were several sub-categories that emerged from each major theme that will be discussed in detail as the primary themes are explored.

##### **School.**

Not surprisingly, the primary theme of school experiences was predominant throughout the parent interviews, and led to the identification of four sub-categories: (a) teacher relationships, (b) academics, (c) inclusion, and (d) teacher assistants.

##### ***Teacher relationships.***

Teacher relationships were the most frequently discussed topic under the broad theme of school experiences. One parent, Noreen, reported mainly positive feedback in regards to her

experiences with teachers, saying that they had all been wonderful with her son, while the rest of the parent participants indicated both positive and negative relations ranging from glowing reviews to allegations of abuse.

In terms of positive teacher relationships, parents reported that important factors were open lines of communication, a collaborative atmosphere, and an inclusive attitude and sense of empathy on the part of the teacher. One parent, Sally, spoke fondly of her child's former art teacher, saying, "...the art teacher was great. We had one of those meetings and he just couldn't see what the problem was, you know?! He was great. He just... didn't see any issue with anything." Noreen shared a similar view of what made a teacher stand out for her: "I guess they just treated them like they were ordinary students."

On the other end of the spectrum, several parents spoke quite candidly about negative experiences with teachers. Three parents highlighted teacher age and "old school" attitudes as having a very negative influence. Gerry and Dorothy spoke of their child's kindergarten teacher as being "too old, out of touch" and went on to state that she was "very cruel to Layla... went over and above the top of what we would probably call abuse today. She just couldn't handle it." They indicated that a teacher assistant had alerted them to what was happening in the classroom, and that it eventually became necessary to move their daughter to another classroom. Gerry and Dorothy, and Gail, also reported having issues throughout school with appropriate seating in the classroom. Teachers were reportedly seating their daughters in the back of their respective classrooms, indicating that the presence of their teacher assistants was too big a distraction for them to be seated near the other students. Gail shared the experience of confronting a teacher about this issue:

I said, 'Why is she not up here?' The teacher said, 'Well, I can't talk over two people,' and I said, 'You know what? She has every right to be there'. And I think they were surprised I would say anything.

Gerry and Dorothy shared similar feelings, saying, "What good does it do sitting in the back of a classroom whispering to a hearing-impaired kid while the others are doing something else?" Another parent, Sally, was visibly angry when sharing a memory of her daughter's Lyanna's high school geography class where she was the only student in the class who was not given a textbook, saying, "[the teacher] obviously didn't value her learning, because she was the one without a textbook... that is just plain discriminatory!"

Essentially, the qualities that parents valued in a teacher relationship were related to equality, to teachers following the premise that all students are entitled to fair and equal opportunities in the classroom. This is directly in line with the Canadian Charter of Rights and Freedoms (Canadian Charter of Rights and Freedoms, 1982), which states that all individuals have a basic human right to fair and equitable treatment, regardless of mental disability.

### *Academics.*

Each parent indicated that overall, their child greatly enjoyed their time in school. Gerry and Dorothy did mention that their daughter, Layla, seemed to enjoy her time in the later grades more, but attributed this to the family moving to rural Nova Scotia from a suburb of a large city. They indicated that the smaller town feel, where "people know people", was a much more relaxed environment for their daughter.

In terms of academics, Gail reported that her daughter, Haily, greatly enjoyed drama, physical education, music, art, science, healthy living, and French, but had difficulty with mathematics: "I never heard her complain about not liking anything in school, except for math,

and even then she didn't complain; she just said that it was really hard". Sally also reported that her daughter, Lyanna, had difficulty with math, saying, "Math was her weak area... she plugged away at it, but..." She also reported that Lyanna enjoyed art, music, drama, geography, English, and history. Gerry and Dorothy indicated that their daughter, Layla, enjoyed mathematics, along with drama and physical education, but did not enjoy art class, which was noted as unusual because today she greatly enjoys painting. Finally, Noreen reported that her son, Albert, enjoyed physical education and music, and was also very interested in learning literacy skills.

All parents indicated that their children had Individualized Program Plans (IPPs) all throughout school, with the exception of Sally, who reported that her daughter, Lyanna, did not have adjusted programming until high school. Parents expressed varying degrees of satisfaction with the design and implementation of these program plans. Noreen was happy with her son Albert's programming, while Gail, Sally, and Gerry and Dorothy indicated that IPPs were not always followed, and often depended on individual teachers. Gail stated:

There were a couple of grades where they weren't always followed... and that was, I think, because of the teachers. And I'm not insulting them, but I think that sometimes when you get 'old school' it's hard to incorporate 'new school' because they are so set in their ways.

As Alton (1998) points out, students with Down syndrome generally show a much wider range of development than their typically developing peers, which may present challenges for school staff in setting appropriate goals in terms of Individualized Program Plan development. The idea that 'old school' teachers were also reported to be the most problematic is also supported by the findings of MacFarlane and Woolfson (2013), who found that teachers with the

most experience also tended to have a more negative view of including special needs students in the regular classroom.

***Inclusion.***

Of the participants, only Sally's daughter, Lyanna, was enrolled in the regular curriculum throughout her entire school career. She reported that her daughter Lyanna was one of the first students with Down syndrome to be placed in regular programming in her town, and as a result, encountered many obstacles along the way:

Sometimes you got the impression that... they resented the fact that your child was in regular school and you were trying to keep it that way... I think they thought having a child with Down syndrome in regular programming was just for the birds.

Sally indicated that there were times in early elementary school when teachers would attempt to adjust Lyanna's outcomes even though she was not on an IPP, and it would be necessary to actually ask teachers to hold Lyanna to the same standard as her classmates. Sally felt that it was important to give the impression that they were very committed to Lyanna's schooling, and as a result, her family made an effort to make attendance a top priority:

We never took vacations... the most we ever took was a long weekend with an extra couple of days, that would be it. Because we wanted to... convey the message that we were serious about her being in regular school... because it was a bit of a struggle sometimes keeping her there when there was a special ed. class down the hall.

Sally noted that grade six was a particularly difficult year for Lyanna, when she moved to a different school and was quite lonely and isolated. Sally stated that:

For that one year... she didn't have anybody in that class. She'd be eating lunch by herself. There were things that happened that year that I was really surprised that the

teacher didn't take any notice of. It was not an inclusive atmosphere that year. It was a tough year. It was really tough.

The three remaining student participants were each enrolled in the regular curriculum during elementary school, and were placed in special education classrooms for junior high and high school. Gerry and Dorothy indicated that there was a definite learning curve for all involved when their daughter Layla started school, as she was also one of the first students with Down syndrome to be enrolled in regular classes in her school. Gail also noted that at times, she was concerned about her daughter Haily being able to fit in with her classmates when at times it was evident that she was on a different developmental level: "and it hurts, as a mom, to see her over there playing with a doll... she was in grade six, you know?" This is reminiscent of Hall and McGregor's (2000) findings that suggest that it is not uncommon for students with Down syndrome to spend increasing amounts of time alone as they progress throughout school, and have more difficulty establishing close social bonds than typical students their age.

### ***Teacher Assistants.***

The role of teacher assistants (TAs) was discussed by each of the parent participants, with mainly positive feedback. Gail expressed a great deal of gratitude towards her daughter Haily's TAs, whose support she felt was vital because some teachers appeared to spend less time and energy on students with exceptionalities. Gerry and Dorothy actually credited their daughter's kindergarten TA with alerting them to the cruel, abusive treatment that she was receiving from her teacher (see Teacher Relationships above), and added, "[the TAs] were as important to her as the teacher all the way through... the relationship with the TA was so significant." Noreen echoed this sentiment, stating that, "[the TA] was with him more than even the teachers, and she would have... more of an idea than the teacher, in some areas." Noreen also questioned the

reasoning behind her son Albert's TA not being invited to meetings. She indicated that when she expressed her desire to get the TA's input, the TA was only invited to one subsequent meeting. Sally did express dissatisfaction with her daughter Lyanna's TA support in grade six, saying, "She'd be out of the class with the TA, not doing very much."

### **Parenting a child with Down syndrome.**

The triumphs and challenges of parenting a child with Down syndrome was also a central theme of the parent interviews. Five sub-categories were identified under this theme: (a) positives, (b) challenges, (c) Down syndrome questions and discussions, (d) how to cope, and (e) how schools can help.

#### ***Positives.***

Hearing parents speak to the positive side of parenting a child with Down syndrome was probably the most interesting, and certainly the most heart-warming portion of each interview. Gail spoke at length about the celebratory atmosphere in their household, and really making an effort to make every small step a "double positive". Essentially, she strove to celebrate any progress or success, no matter how small or how delayed, because in her eyes, they were all major steps, and big accomplishments for Haily.

Gerry and Dorothy indicated that the challenges involved with parenting a child with Down syndrome can actually be a positive, in this memorable exchange:

*Gerry:* That's part of it, being creative, and when something didn't work, you had to try something else.

*Interviewer:* You had to stay on your toes, find new things?

*Gerry:* Exactly. But that gave us life too, on some level.



Gerry was also struck by the way his life with Layla has come full circle, in that she is now taking on more of a caregiving role: “Well, that’s what happens as I get old. Layla is really taking care of me now. She brings me my tea, and even brings me my slippers, and this isn’t protocol here by the way! (laughs) But it’s quite touching.”

Sally indicated that her daughter’s temperament made her a pleasure to spend time with. She went on to say that “People with disabilities are generally...they’re cheerful and they’re happy, and you can’t say that about the rest of us a lot of the time!” Noreen echoed these sentiments, saying that her son has a great sense of humour, is fun to be around, and is very helpful around the house.

### ***Challenges.***

One parent who once worked in the school system was able to offer some unique insights into the challenges of parenting a child with Down syndrome, as she was often privy to more information and witnessed more of her daughter’s peer interactions than the other parent participants. She indicated that her biggest challenge in this role was seeing her daughter often on the outskirts of social circles, and hearing other students make comments about her speech. She did indicate that these difficulties were mostly in early elementary school:

I saw that mostly in the younger grades. I went to her school when she was in grade two, so I would see when I was on duty and when I’d be out and travelling on a bus... you’d hear comments made... as a mom, that was challenging for me.”

Interestingly, most of the challenges that Gerry and Dorothy described were in their struggles to provide Layla with an inclusive education. Gerry indicated that there was “a defensiveness” on the part of school officials in the early years, and when they felt that student services were somewhat lacking, the school was not receptive to outside consultants that Gerry

and Dorothy would suggest. Dorothy also pointed out that it was very difficult to balance the frequent meetings with her career:

You need a lot of stamina, really, to keep up with the system. You need a lot of stamina, and a lot of time. It's a huge commitment... and from what I read, for most couples, somebody – usually the mom – has to quit work and stay home, because it takes so much time to go to those meetings and such.

Gerry and Dorothy also indicated that their difficulties did not end when school would let out for the summer, as even when their daughter, Layla, was a teenager she still required supervision during the daytime, which was an added financial strain.

Sally, who kept her daughter, Lyanna, in regular classes throughout her school career, also commented on the difficulties of balancing work and parenting, saying, “If I were working I wouldn't have been able to pull it off... Lyanna was in regular school but she was [basically] homeschooled at the same time”.

***Down syndrome questions and discussions.***

A common theme for all parents interviewed was whether and when to have an open discussion with their child about Down syndrome. Gerry and Dorothy indicated that they had never had this conversation with Layla, as she had never asked questions or given any indication that she saw herself as being different from typically developing children. Both Noreen and Sally reported that they waited until their children were older to have this discussion. Sally indicated that she felt that her daughter, Lyanna, “wasn't ready” until after high school, but that today Lyanna talks openly about Down syndrome and is a strong self-advocate. When asked if Lyanna ever asked questions when she was younger, Sally replied, “No, but she probably knew, and maybe she was bothered by it. But we just kind of treaded carefully on that... and waited until

she was ready”. Similarly, Noreen also reported that her son, Albert, had not asked any questions while growing up, but that she talked with him about having Down syndrome when he was older and she felt that he was ready: “I told him... and this was really just a few years ago, that he was born with Down syndrome, and that he was the only one in the family that had Down syndrome, and that [he’s] lucky”.

Gail was the only parent who indicated that she made her child aware of having Down syndrome at a young age. She felt that it was important for Haily to know that “It takes all kinds... if we were all the same, it wouldn’t be much fun”. She indicated that when Haily asked why she was born with Down syndrome, it was a matter of explaining that all people have different abilities, both mental and physical, and that Haily was special in her own way. Haily learned not only to accept this, but embrace it: “She would say, ‘Hi, my name is Haily, this is who I am. This is my age, this is my mom, this is my dad, and I have Down syndrome’. That’s how she’d introduce herself!”

### ***How to cope.***

As mentioned above, there were many challenges highlighted in parenting a child with Down syndrome, and as parents, coping with these challenges could be an exhausting and draining task. Gerry and Dorothy shared some innovative ways that they had learned to cope with their unique parenting demands. Realizing the importance of not only talking about their experiences, but also supporting others in similar circumstances, they formed their own support group with several other local families who were raising children with exceptionalities:

The Ups and Downs Club, we called it. And it was exactly what it sounds like. It was for fun, but it was also a place of support. We’d come together with a glass of wine and a plate of cheese, and we’d share what we had lived for that month. There were six families

there, and I found that quite helpful... it brought back our perspective and sort of energized us again.

Gerry and Dorothy were also responsible for founding a small summer camp for local children with exceptionalities, both as a way of providing summer recreation for a population that did not have many options locally, and also as a form of respite and support for local families. Also, as mentioned earlier, when Gail realized that her daughter was reaching her developmental milestones much later than other children her age, rather than focus on these delays, she chose instead to focus on celebrating any and all gains.

***How schools can help.***

At the conclusion of each interview, parents were given the opportunity to reflect on their experiences and offer suggestions for ways that the education system could adapt to better meet the needs of students with exceptionalities and their families. Each parent was able to offer very unique ideas and insights. Interestingly, each parent also offered very *different* ideas and insights, perhaps suggesting that the priorities of individual families may play an important factor in satisfaction with their child's education, reinforcing the need for schools to approach each family on an individual basis, rather than a one-size-fits-all programming approach.

For Gail, communication, collaboration, and an open mind were of paramount importance:

Make sure there's a lot of communication between school and home. You've got to work together as a team. You've got to be positive. Don't look at all the disabilities, look at the abilities... and see what they are capable of doing. It's all about working together as a team, and no question is a silly question. Ask it if you're not sure. *Ask it*. If you're feeling a bit overwhelmed, or you're feeling that there's friction, then talk about it. Please don't

go to other people and say, 'So-and-so is doing this'. Talk to me. Parent-teacher relationship. Don't call the principal and say, 'We're setting up a meeting'.

Communication is a big key factor. And teachers have to be on board.

Gerry and Dorothy did express a similar sentiment to Gail in terms of changing the way that students with exceptionalities are viewed:

That is what would be great to see, more of that philosophy in schools of thinking about what the gifts are that these people bring to the school, and how we can help the other kids discover that, rather than just seeing them as... different.

They also felt that families were often at a loss as to how to "navigate the system", and would benefit greatly from some assistance, either in the form of a parent-school liaison to inform parents of available resources and avenues, or perhaps through a mentoring program wherein parents who have already sent children with exceptionalities through school could be available for support and guidance.

Gerry and Dorothy acknowledged that great steps have been made in terms of early intervention support, but stressed the need for this support to extend into the school years:

One thing that you have now, that we didn't have, is a fantastic early intervention program up until they start school... and then you're dropped like a hot potato. Maybe it's not the school's mandate, I understand that, maybe it is a community service question. Who cares for the family for all of those hours that the child is not in school? The family needs support still. Again, maybe it isn't a school issue, but you do feel really abandoned at that stage.

Sally's concerns were mainly in regards to her daughter's social isolation in school. She felt that there were times when Lyanna was very lonely, and did not know how to approach

others and establish friendships. Sally felt that Lyanna would have benefited greatly from some sort of program aimed at social integration, such a friendship circle, that would bring together students both with and without exceptionalities in order to build a shared understanding and establish a strong social network.

Noreen appeared to be largely satisfied with her experience with the school system, but did mention that there were times where her son could have been included in more of the extra-curricular events at school, such as concerts and talent shows. She reported that Albert loves to sing, and would have loved to share his talent more at school.

#### **Extra-curricular activities.**

The subject of extra-curricular activities was discussed by each parent, with largely mixed feelings about the availability of recreational activities in the school setting. Sub-categories that emerged were (a) school based activities, and (b) outside agencies/organizations.

#### ***School-based.***

A common theme across all parent interviews was that there were very few options available for their children in terms of extra-curricular activities offered in school. Both Noreen and Gail indicated that their children were involved with a school swim program. Gerry and Dorothy and Sally also indicated that their children each took part in a school talent show. Gerry and Dorothy also reported that they attempted to get their daughter involved with the track and field team, but the school did not allow it:

*Interviewer:* Were there any extra-curricular activities that Layla was really into?

*Dorothy:* In school, provided by the school?

*Interviewer:* Provided by the school.

*Dorothy:* No. No. Never anything, I would say. Do you remember any Gerry?

*Gerry:* (shakes head)

*Interviewer:* Because there was nothing available?

*Dorothy:* No. Now, there might be now, I'd like to think there is, but I don't know. As I said, I tried to get her into the track and field thing, but that was a dead end.

It may be worth noting that these concerns about a lack of available extra-curricular activities may not be exclusive to students with exceptionalities. A glance through any high school yearbook will usually show that most committees and athletic teams are made up of many of the same people, perhaps implying a larger, systemic problem, in that school based extracurricular activities, in general, can be somewhat elitist in nature and accessible to only a select few. That said, research has shown that students with Down syndrome are less likely to be involved with team sports or activities, and are predominantly involved with solitary and sedentary pastimes (Oates, Bebbington, Bourke, Girdler, & Leonard, 2011).

Parents of two students indicated that the senior prom was a significant event for their children. Gerry and Dorothy went on to share that initially, the school was opposed to Layla attending, as they did not feel that they could offer sufficient supervision. Gerry and Dorothy arranged for chaperones to accompany Layla and her date, and the school agreed to the arrangement.

Parents of two students also indicated that their children regularly attended school dances, although Sally indicated that initially, Lyanna had a difficult time coping with the volume and visual overload of such an event:

Lyanna was in grade 7, they had a school dance. It was in the fall. So this was her first school dance, and her best friend, Kathy, they were going together. So, I went in to see how things were going, and probably the dance had been going on for about an hour. And

there were strobe lights. And I could see Kathy in the hall, and I said, “Any sign of Lyanna?” It was dark in there, and there were strobe lights, and the music was loud. Oh my god, it was loud! And Lyanna was in a corner, she was just melting away. There was so much sensory overload, so I talked her into coming home, and she was crying in the car coming home... and I was crying in the car coming home. And I thought, well, this will be the end of the dances, I won’t have to deal with this anymore... [but] no! She went to the dances after that all the way through school and high school and everything else.

***Outside agencies/organizations.***

A common theme across parent interviews was that while their children were very active in many different organizations and activities, the majority of these were not offered in the school setting. As Sally put it: “She had all kinds of extracurricular activities in her life, starting with dance, and scouts and guides... girl guides and brownies... music lesson... therapeutic riding and swimming. Whatever was going, she was into, but not at school”. All participants are currently very involved with the Special Olympics, but only Gerry and Dorothy reported that their child was involved during her school years. They also revealed that they had some reservations about Layla taking part:

*Interviewer:* Was Layla involved with Special Olympics when she was still in school?

*Dorothy:* Yup. She started right away when we moved here. Initially, I never thought it was a good thing, but then I thought, well, if other kids have their medals from hockey and gymnastics and stuff... but then, of course, she was very successful. She was chosen to go to provincials the first year that we were here...

*Gerry:* You know, theoretically, we didn’t think this segregation model was a good thing,



but truthfully, it's always a balance, and in the end we kind of realized that Layla was more relaxed and enjoyed it so much.

Sally also spoke to experiencing trepidation when considering whether or not to enrol Lyanna in Special Olympics. Ultimately, she decided against it, saying that when she and her husband made the decision to enrol Lyanna in regular classes, they also decided that they did not want Lyanna separated from her typically developing peers for any reason.

### **Friendship.**

Another common theme (and concern) was the subject of friendships. Conversations regarding the establishment and maintenance of friendships led to the identification of four sub-categories: (a) naturally-formed friendships, (b) friendship groups/programs, (c) interactive settings, and (d) concerns.

#### ***Naturally-formed friendships.***

Each parent reported that their child had been able to naturally form friendships in the same ways as their typically developing peers, either at school or with other children in their neighbourhoods. Gail reported that as far as Haily's friends were concerned, there was no difference between them, saying, "They were about a year apart, she never asked anything about Haily, because she never saw that there was anything different about Haily. She never, ever, questioned anything that Haily had done, she never said anything. She'd just always want to be with her". These results are encouraging, as previous research has shown that many children with Down syndrome struggle to establish and maintain friendships, with as many as one third reported as having no friends (Rosner, Hodapp, Fidler, Sagun, & Dykens, 2004).

#### ***Friendship groups/programs.***

A program aimed at building friendships that was mentioned by two different families is the Best Buddies program. This program is a partnership between a local university and community organizations that pairs students with exceptionalities with university students. The pairs generally meet once each week to engage in a fun activity, such as bowling, seeing a movie, or simply going out for coffee and a chat. Noreen mentioned Albert's Best Buddy as being a close friend, and Gerry and Dorothy spoke about the lasting friendship that Layla formed:

Her first Best Buddy was from Newfoundland, and she graduated [from university] when Layla graduated from high school, and they had their pictures taken together for graduation, and it was so cute. It was the cutest picture. And then Layla went and stayed with her for a week and went to the Magnetic Hill Zoo in Moncton.

Gerry and Dorothy also added that Layla had recently taken a trip to Newfoundland to visit her old Best Buddy, and indicated that both parties were delighted to be reunited. They also mentioned that two Best Buddies from the university acted as chaperones to accompany Layla and her friend to her high school prom.

The importance of these types of groups cannot be understated, as the majority of student with Down syndrome report very little social interaction with friends outside of school (Rosner, Hodapp, Fidler, Sagun, & Dykens, 2004). Encouraging social interaction in a variety of settings may be very beneficial in helping these students to establish lasting bonds and social support.

***Interactive settings.***

All parents interviewed indicated that to a large extent, their children did not have a great deal of interaction with friends outside of school. Noreen and Sally both indicated that their children would attend occasional birthday parties and also occasionally have visitors. Gerry and

Dorothy reported that Layla would rarely see friends outside of school: “More at organized activities. There wasn’t a ton that I could think of. Sometimes she would have a friend over to watch a movie or something... most of her social life was with family, though”. Gail also indicated that she was hesitant, at times, to arrange for Haily to see friends outside school, out of concern that her friends would rather “do their own thing” with other typically developing peers. Noreen also expressed concern about Albert’s friends “outgrowing” him.

Regarding in-school interactions with friends, the one parent who indicated that her child experienced significant difficulty was Sally, who is also the one parent whose child was enrolled in the regular curriculum throughout her school career. Sally reported that Lyanna began having difficulty in junior high, where she would eat her lunch by herself. Sally went on to indicate that high school in particular were a very difficult time for Lyanna:

And in high school, friends... that was tough. Sometimes she just wouldn’t really have anybody to chum with... she’d be feeling really isolated. You know how it is. You can be a perfectly normal kid in high school and feel isolated, so for Lyanna...

That the one student who was in regular classes throughout school had the most difficulty socially could be indicative of a serious problem with the inclusion model. It seems that it would have been very beneficial for this student to receive some intervention in social skills training, or perhaps a friendship group aimed at social integration.

### **Bullying/teasing.**

Unfortunately, the unpleasant subject of their child being bullied or teased was discussed by parents of three students. Gail indicated that in her elementary years, Haily would often be the target of verbal comments, usually directed towards her speech difficulties: “Sometimes they... [would] just be really nasty. She was hard to understand, it wasn’t as clear, and they would make

comments like, ‘Oh, she just said something weird’, or they’d kind of give her a look”. It is encouraging that Gail also noted that there were many occasions where fellow students would defend Haily and report these incidents to teachers. Noreen reported that at times, Albert complained about other students staring at him, while Gerry and Dorothy indicated that Layla was involved in incidents on the school bus where other students would take advantage of her by convincing her to be the agent in mean pranks: “In elementary, in those early years... there were some kids on the bus who would goad her into doing things, like getting her to hit boys in their privates”. It is disturbing that a full 75% of student participants were reported to have experienced some form of peer victimization, given that estimates of this type of behaviour among typically developing peers are closer to 30% ( Nansel et al, 2001; Flynt & Morton, 2004).

### **Speech difficulties.**

The importance of speech/language skills was discussed by parents of three different students. Communication difficulties are common among children with Down syndrome, with a full half of these children requiring help or supervision to communicate (Leonard, Msall, Bower, Tremont, & Leonard, 2002). Sally indicated that her decision to place Lyanna in the regular school curriculum was heavily influenced by her verbal ability, saying, “It had never crossed my mind [to put her in regular classes]. We had her in daycare... and her verbal skills were good, and they said, ‘You have to put her in regular school!’ So that’s kind of where that came from”.

Gerry and Dorothy spoke about being frustrated with the lack of speech-language services available at the time that Layla was entering school. Layla’s speech had been impacted by hearing loss as an infant; however, her school did not have a Speech Language Pathologist on staff with student services. Gerry and Dorothy pushed for the school to allow Layla to work with a Speech Language Pathologist, but met resistance:

*Dorothy:* We would come in bringing different consultants that we wanted her to work with and the school wouldn't allow it.

*Gerry:* We were just trying to be helpful, in recognizing that the school was new at this, so let's all find of figure it out together?

*Interviewer:* Let's all put our heads together?

*Gerry:* Yeah. And I think sometimes they really just went through the motions. There were some really exceptional people...

*Dorothy:* So many great consultants, you know, speech-language and whatever, but they did finally let someone come in, and this lady was really, really, good. She gave all kinds of techniques for reading, and it was really good, but then her supervisor said that Layla would never use speech as a form of communication so they couldn't continue. (Author's note: Today, Layla is proficient in basic sign language, but does, in fact, use verbal language as her primary form of communication)

As mentioned above, Gail reported that Haily's speech difficulties would at times lead to social difficulties, saying, "With speech... a lot of people couldn't understand her, and that would lead to frustration, especially with kids". This is supported by Kumin's (1994) findings that roughly 95% of parents of children with Down syndrome reported that people outside of their immediate family were unable to understand their child's attempts to verbally communicate. Gail indicated that other students would often make "cruel" or "nasty" comments about her speech difficulties in early elementary. She also indicated that these comments were more due to immaturity than malice, and the comments generally stopped as Haily got older and her peers became more accepting of who she was:

One of the teachers had a talk with the whole class, and talked about how we're the same, and how we're different, and one of the kids spoke up and said, 'You mean like Haily! Sometimes we don't know what she's saying, but we really like her!' And this is where [we started to see] these changes happening.

### **Findings and Discussion – Student Data**

The student participants, as a whole, were very enthusiastic and open about sharing their school experiences. Primary themes that were identified from the student interviews were very similar to those identified in the parent data: 1) School; 2) Down syndrome; 3) Friendships; 4) Bullying/teasing; and 5) Extra-curricular activities. Again, there were several sub-categories that emerged from each major theme that will be discussed in detail as the primary themes are explored.

#### **School.**

The subject of school experiences was discussed in depth by each student participant. During the course of these discussions, two distinct sub-categories were identified: (a) academics, and (b) teacher relationships.

#### ***Academics.***

Overall, each student indicated that they enjoyed their time in school. In terms of academic classes, Albert reported that he enjoyed language arts, drama, math, and physical education. Haily indicated that she enjoyed physical education and drama, but did not enjoy mathematics. Layla reported enjoying math, drama, home economics, reading in the library, and physical education, but did not enjoy art class. This is a rather interesting disclosure, as today, Layla is an accomplished painter who has displayed and sold her artwork at many local shows and galleries. Most of her work is very abstract and freeform, so it is possible that a structured

class with specific assignments did not allow her the artistic freedom that she needed to find her own style. Lyanna reported that she enjoyed art, drama, and resource, but had more difficulty with English literature in high school, saying, “I couldn’t really understand English. Like, learning about Shakespeare”. She was also brutally honest regarding her struggles with mathematics, saying, “I *sucked* at math”. As Lyanna was the lone student who stayed in the regular curriculum throughout school, her distaste for literature and math may speak to inappropriate programming on her Individualized Program Plans, which are meant to adjust academic outcomes to an appropriate level for the individual student.

Sadly, the majority of student participants reported a preference for the arts and physical education, both areas of the current curriculum that are being slowly whittled away in most schools.

### ***Teacher relationships.***

Encouragingly, all of the students interviewed indicated that they had positive relationships with their teachers. Even Layla, whose parents had described her kindergarten teacher as being very cruel towards her, reported liking all of her teachers, but it is possible that she was too young at the time to understand her teacher’s behaviour. Albert and Haily cited their teachers’ kindness as being an important factor, while Lyanna was grateful for the extra time and help that her teachers were willing to give.

### **Down syndrome.**

Of the four student participants, three had an understanding of Down syndrome. Albert and Haily both indicated that Down syndrome is something that people are born with, and Lyanna further elaborated by saying, “I think it’s kind of an illness for some people”. However, far from seeing this “illness” as a negative, Lyanna went on to say that, “It’s wonderful to be a

part of”. Albert indicated that Down syndrome did not affect his independence, and that he was still able to walk to town by himself. Haily also commented that a girl that she knows with Down syndrome is a “really good girl”, and a good friend. Perhaps it is telling of the way that their parents chose to discuss Down syndrome with their children, but none of the participants used the word ‘disability’ to describe Down syndrome, and instead shared only positive attributes.

### **Friendships.**

All of the student participants discussed the topic of friendship, with three sub-categories identified: (a) naturally formed friendships, (b) friendship groups/programs, and (c) interactive settings.

#### ***Naturally formed friendships.***

Each student indicated that they had met and established friends on their own. Albert reported playing with boys in his neighbourhood, while Haily and Layla reported that most of their friends were from their class at school. Lyanna talked about meeting her best friend (then and now) “in the early years of dance class”. Again, it is very encouraging that all student participants reported having friends in school, as the importance of social support has been described as a preventative agent against stress and crisis situations (Saylor & Leach, 2009).

#### ***Friendship groups/programs.***

Lyanna spoke enthusiastically about Best Buddies, a friendship program that she began taking part in when she was in high school. The impact of this program has been discussed by two different parents above. Here, Lyanna offered her view:

It’s a really fun program. [We] team up with a university student. It’s so much fun! [We] get together, and do lots of fun stuff, like going to the café on weekends and stuff. And don’t forget the open jam at the Legion!



Lyanna continues to be involved with this program today, and has made and maintained many lasting friendships throughout the years. These friendships may have been especially important for her during her high school years, when her mother indicated that she was often lonely and isolated.

***Interactive settings.***

Haily indicated that most of her friends were students from her classes at school, and also indicated that she did not often see her friends outside school, saying, “I didn’t usually see them on weekends. I was usually home”. In contrast, Albert reported going bowling with his friends, Layla mentioned having friends over for her birthday parties, and Lyanna talked about going for sleepovers, meeting at a café, and attending musical performances with friends.

***Bullying/teasing.***

Unfortunately, the subject of bullying/teasing was discussed by two students, with three subcategories identified: (a) verbal abuse, (b) physical abuse, and (c) impact. The fact that half of the student participants freely spoke about being either verbally or physically abused (or both) speaks to the vulnerability of this student population, as estimates for typically developing peers are placed much lower (Nansel et al., 2001, Flynt & Morton, 2004).

***Verbal abuse.***

Both Lyanna and Albert spoke about being verbally taunted by classmates. Lyanna spoke about being teased by what she called “the popular crowd”. The fact that the students that were targeting her were also the ones who held the most social influence is deeply troubling. These are the very students whom much of the student population look to for social referencing, and is perhaps indicative of a need to create more peer advocacy for students with exceptionalities.

Albert also spoke about being teased and taunted by fellow students, saying that “Oh, there would be some people [who were] mean, rude to me”, and actually used the word “bully” to describe one of these students:

*Albert:* I wanted to be there, but someone was a bully.

*Interviewer:* A bully?

*Albert:* Yeah, a bully. They were cursing, using bad words.

*Interviewer:* Oh no. Was this at school?

*Albert:* Yeah, at school. And walking to school.

*Interviewer:* There was somebody bothering you at school?

*Albert:* Yeah, they wouldn't stop bugging me.

*Interviewer:* Did it happen a lot?

*Albert:* Yeah, too much. They [were] mean.

On two occasions, Albert indicated that people would taunt him “right in my face”, and said that these experiences left him wishing that people wouldn't “be mean to me”.

Unfortunately, Albert's difficulties did not end at verbal teasing, as some people chose to escalate their behaviour into physical violence.

### ***Physical abuse.***

The most disturbing part of Albert's account of physical abuse is that his attackers were not children. They were university students. While being a child is by no means an excuse for cruel behaviour, such behaviour is perhaps more forgivable in children in that they may not be old enough to know any better. Albert's tormentors were certainly old enough to know better:

*Albert:* Some people [were mean].

*Interviewer:* Some people, yeah. Teachers, or students?

*Albert:* Students. University students.

*Interviewer:* University students?! They were mean to you?

*Albert:* Yeah, they were staring at me, talking right in my face. Some were bullies. I couldn't go for a walk.

*Interviewer:* Couldn't go for a walk?

*Albert:* Yeah, they kicked me.

*Interviewer:* Oh, Albert, I'm so sorry to hear that.

***Impact.***

These memories were clearly upsetting to Albert, but he also appeared to want to talk about them. At the very onset of his interview, when told that the interviewer would be asking questions about school, Albert immediately said, "People were bugging me". Furthermore, he often steered the interview back to the topic of bullying when the interviewer was attempting to redirect him to other subjects. This speaks volumes to the lasting trauma that these experiences had on this young man. When asked how he felt when being bullied or teased, he replied that it was "awful" and made him feel "angry" and that people should not treat him that way:

*Interviewer:* How did that make you feel?

*Albert:* I felt like people shouldn't be mean to me.

*Interviewer:* Did you feel kind of sad?

*Albert:* I felt angry.

*Interviewer:* Angry?

*Albert:* So angry. And I'd do like this (shakes his fist).

*Interviewer:* And they'd leave you alone?

*Albert:* Yeah, I'd get mad and they'd leave.

Lyanna also spoke about the impact of being teased at school, saying that it “hurts your feelings”. Luckily, she also reported that when students were making fun of her, her parents, teachers, and especially her big sister were quick to come to her defence.

### **Extra-curricular activities.**

Haily was the only student interviewed who reported being involved with any school-based extracurricular activities (girls football). Lyanna and Layla indicated that they were both involved in a number of activities and organizations outside of school, such as horseback riding, working out, dance classes, Girl Guides, and Brownies. Albert indicated that he enjoyed going bowling with friends. Again, it is possible that the lack of available activities may not be exclusive to this population of students, but a larger problem of most activities being dominated by an elite group of athletically, academically, or socially gifted students.

### **Summary**

After careful analysis of both parent and student data, several major themes were identified for each group. Within these themes there were also several sub-categories identified. Taken together, the data offers detailed insight into the positive and negative school experiences of both students with Down syndrome and their parents.

For parents, primary themes that were identified included: School, Parenting a child with Down syndrome, Extra-curricular activities, Friendship, Bullying, and Speech difficulties. When examining the broad topic of school, the sub-category of “Teacher Relationships” was prominent, with parents sharing both positive and negative stories about teachers that they had encountered. The general consensus among parents was that the teachers that had made a difference in their children’s education took pains to treat them like normal students. Communication between teachers and parents was stressed as being a vital component to a

strong relationship, as well as a collaborative effort between home and school. In almost direct contrast, parents indicated that the negative teacher relationships that stood out for them were related to teachers treating their children as different, and not providing them with the same materials or learning opportunities as their peers. Another sub-category that emerged was “Academics”. All parents indicated that their children enjoyed their time in school. Their children generally favoured the arts and physical education, with mathematics cited as an area of difficulty by two parents. Parents expressed mixed opinions about the effective implementation of Individualized Program Plans throughout their children’s schooling, indicating that effective programming depended largely upon the classroom teacher. Another sub-category that was identified under the broader theme of school was “Inclusion”. Only one student participant had remained in regular programming throughout school, and her mother described the experience as a “minefield” in that many teachers and administrators were either unprepared to provide appropriate programming for her daughter, or were unwilling. Another sub-category that was identified was “Teacher Assistants”. Parents described the role of the Teacher Assistant (TA) as vital to the success of students with exceptionalities, and even indicated that the relationship with the TA may be more important than the teacher.

Parents also offered many insights into the experience of parenting a child with Down syndrome. One sub-category that was identified was the “Positives” of this unique experience. Parents indicated that the humour and temperament of their children made them fun to be around, and that the added challenges associated with parenting a child with exceptionalities required a great deal of creativity, which could actually be invigorating and satisfying. Delays in developmental milestones simply meant that even the smallest steps forward became reasons for great celebration. Along with the positives, another sub-category involved “Challenges”. Parents

indicated having difficulty watching their child struggle socially, as well as struggling to balance frequent school meetings and added parenting demands with a career. Another sub-category that was identified was “Down syndrome questions and discussions”, involving how to answer difficult questions from their child, and if and when to have an open discussion about Down syndrome. One parent elected to talk openly and honestly about Down syndrome with her daughter at a very young age in order to normalize it, while two others chose to wait until their children were much older. One couple indicated that they had never told their daughter that she had Down syndrome simply because she had never asked questions or indicated that she saw herself as different from her typically developing peers. Another very interesting sub-category identified was “How to cope”. One couple was very proactive in taking stock of community resources and making attempts to fill any gaps, by forming their own support group for parents in similar situations, and eventually founding a summer camp for students with exceptionalities, both to provide recreation for children and respite for families. One final sub-category that was identified under the broad theme of school was “How schools can help”. Parents expressed several insightful ideas regarding how schools could improve the experience for other parents in the future. A greater focus on abilities rather than disabilities was a sentiment echoed by parents of two different students. Other ideas included parents being able to help each other through mentoring programs, a parent-school liaison to help parents navigate the system, social skill and/or friendship building programs, and greater involvement in school activities and events.

The theme of Extra-curricular Activities was identified, with two sub-categories, “school-based activities” and “outside organizations”. Parents reported that there were few to no options available for their children at school in terms of extra-curricular activities, although prom and school dances were identified as positive experiences. Parents indicated that their children were

very active with a variety of activities and organizations outside of school, such as Girl Guides, Brownies, dance classes, bowling, and music. The Special Olympics was frequently mentioned as being a wonderful experience for students, although parents also admitted to having reservations about the segregated nature of the games.

Another major theme that emerged was Friendship. Sub-categories emerged regarding “Naturally formed friendships”, “Friendship groups/programs”, and “Interactive settings”. Parents reported that peers were typically very accepting of their children, and that they had little difficulty establishing and maintaining friendships with classmates and neighbourhood kids. That said, parents also reported that their children benefited greatly from friendship programs such as Best Buddies, which have created many rewarding and lasting relationships. In terms of interactive settings, parents indicated that they made efforts for their children to interact with friends both in and out of school, although two parents did express some concerns about their children’s peers “outgrowing” them or developing different interests.

Bullying/Teasing was another major theme. While no parents indicated that their child had been physically abused, there were complaints about students staring, making mean comments, and goading a child with Down syndrome into inappropriate behaviour on the school bus.

One final major theme was focused on Speech Difficulties. One parent spoke about her child’s verbal skills being an important factor in the decision to enrol her in regular classes, while another expressed frustration at the lack of speech-language services available to her child when she started school. Finally, speech difficulties were highlighted by one parent as a point of ridicule for her child at school, as students would often make mean comments in early elementary school about her enunciation problems.

For students, primary themes that were identified were: School, Down syndrome, Friendships, Bullying/teasing, and Extra-curricular activities. When examining the broad topic of school, the subcategory of “Academics” was identified. Overall, each student indicated that they enjoyed their time in school. The arts and physical education were overwhelmingly chosen as favourite classes, while two students identified mathematics as a significant struggle. Another subcategory identified was “Teacher relationships”. All students indicated positive relationships with their teachers, with exceptional teachers being noted as ones who were very kind and helpful.

When discussing the primary theme of Down syndrome, three out of four students talked about their understanding of Down syndrome. Two students indicated that Down syndrome is something that you are born with. The third participant described it as an “illness” but also went on to say that “It’s wonderful to be a part of”. At no time did any students use the word “disability” to describe Down syndrome, and instead shared many positive attributes.

Friendship was a primary theme that emerged based on concepts such as how friendships were formed (subcategories “Naturally formed friendships”, and “Friendship groups/programs”) and where students saw the most of their friends (“Interactive settings”). All students reported forming and establishing friendships naturally, either with other children who lived nearby, classmates at school, or through other activities, such as dance class. One student also enthusiastically described her experiences with Best Buddies, a program that pairs a student with a disability with a university student to share recreational outings during the school year. Three students reported seeing their friend regularly outside of school for activities such as parties and sleepovers, while one student reported that most of her peer interaction took place at school.



Sadly enough, the primary theme of bullying was identified, with the subcategories of “verbal abuse”, “physical abuse” and “impact. One female student spoke about being verbally taunted by what she called “the popular crowd”, while a male student talked about being verbally assaulted both at school and while walking to school, and also of being harassed and even kicked by a group of university students. Both students indicated that these experiences were very hurtful, and the male student reported that it made him very angry, and that he would often have to shake his fist to make people leave him alone.

The final primary theme identified was discussion of available extra-curricular activities at school, with the general consensus that there were few options. While all of the participants reported being taking part in a number of activities outside of school, such as bowling, horseback riding, working out, dance classes, Girl Guides, and Brownies, only one student reported involvement with a school based activity (girls football).

### **Conclusions and Recommendations for Future Research**

The findings from this exploratory qualitative study shed some light on the school experiences of individuals with Down syndrome (and their families) in a rural Canadian town. Through the process of thematic analysis, several important issues were examined that affected both parents and students as they navigated the modern school system, both in and out of inclusive classrooms. The qualitative methodology was very important in allowing in-depth insight into the experiences of these students and their parents. Curtin and Clarke (2006) posit that inclusive schools are morally and ethically correct, and also offer greater exposure to academic and social benefits for students with exceptionalities. The results of this study suggest that these benefits may not be as evident as would be hoped for students with Down syndrome, and that schools may still have a lot of work to do in order to fully support these students and

their families. The fact that participants and families showed very similar experiences despite the fact that they graduated over a span of ten years suggests that schools may not be evolving in their programming for students with Down syndrome. Further research into this area will be very important in improving the school experiences of students with Down syndrome and their families in the years to come.

In regards to purported academic benefits, it is interesting to note that three out of four student participants were pulled from the regular curriculum upon entering high school. Only one student remained in regular classes throughout her school career, and according to her mother, was able to do so only through huge efforts at home and at school. Even then, this student reported being overwhelmed by high school math and Shakespeare, and her mother reported numerous difficulties with appropriate programming and teacher attitudes. Students with Down syndrome generally develop skills at a slower rate than typical students their age, which means that they learn skills later and take longer to master them, which in turn means that the gap in learning between them and their typically developing peers grows with age (Alton, 1998; Curtin & Clarke, 2005). This means that by the time a student with Down syndrome enters high school, he or she may already be significantly behind at a time when learning and workload demands increase dramatically. Without effective program planning in place, even with extensive home support it may be a monumental task for these students to stay afloat. Research aimed at closing this gap may be essential for school success as students with Down syndrome transition to secondary school.

Socially, attending a mainstream school is intended to expose students with Down syndrome to a wider variety of experiences and peer interactions, and also promote understanding and acceptance among typically developing peers (McAllister & Hadjri, 2013;

Curtin & Clarke, 2005). The results of this study suggest otherwise, with parents and students reporting a woeful lack of available extra-curricular activities at the school, and even encountering resistance to participation in some sports and social events. Additionally, two out of four students reported experiencing bullying (one female student spoke about being verbally taunted, while a male student talked about being stared at, cursed at, and even kicked). Another students' parents also indicated that she had been tricked into engaging in inappropriate behaviour on the school bus. These findings support Flynt and Morton (2004) who found that students with disabilities were more likely to be bullied than their typically developing peers. Research indicates that children with Down syndrome show subtle differences in the development of social cognition, which could lead to deficits in the understanding of social interactions (Cebula, Moore, & Wishart, 2010). What this indicates is a need for further study into the development of social skills for these students. School can be a minefield for anyone to navigate, let alone a student who may have difficulty understanding aggression or anger in their peers, and this may also indicate a need for further study into the reasons that these students are being singled out for abuse, and finding ways to turn this cruel behaviour into something better, something kinder. Education is indeed a basic human right, and this study recognizes the courage and determination of each and every participant who managed to navigate through a school system that maybe was not quite ready for them.

### **Limitations of the Current Study**

There are certain limitations that must be taken into account when considering the results of the current study. As the subject matter was, at times, of a sensitive nature, it is possible that some responses may have been influenced by an urge to satisfy social desirability. It may also be difficult to generalize based on these findings, as the sample size in the current study is relatively

small, and for the most part, attended the same schools. That said, the study does present a clear and detailed picture of the experience of these individuals that others may be able to recognize as part of their own experience. The current study may have also been limited in that only one male student and one male parent volunteered to participate. There may be subtle differences in the experience of male and female participants that has not yet been fully explored.

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## Appendix A

### Invitation to Participate (Student Participant)

**Title of Research:** School experiences of individuals with Down syndrome: Issues surrounding inclusion

**Name of Researchers:** Hugh MacDonald, MA School Psychology student, Mount Saint Vincent University; Dr. Mary Jane Harkins, Department of Education, Mount Saint Vincent University

#### What is the study about?

This study will invite young men and women with Down syndrome to share their memories and feelings about their time in school.

#### What will I be expected to do?

Your participation is voluntary. That means that you won't have to do anything that you don't want to. If you would like to be in the study, the first thing you'll do is sign your name on a form. This will show that you understand what the study is about, and that you want to be a part of it. You will be given a copy of this form to keep. Next, the student researcher, Hugh MacDonald, will interview you. He will ask you some questions about things that you remember about school. He might ask you to talk about your favourite things about school, and your least favourite things. The interview will probably take about half an hour, or maybe a bit longer if you have a lot to share. We can do the interview one-on-one, or you can have your parent in the room too if that would make you more comfortable. It is up to you and your parent. Everything that you say will be confidential. That means that you can share private thoughts and feelings, and nobody will find out that it was you who shared them.

#### Will anyone know what I said?

After all of the interviews, the student researcher will write a paper about everything that he learned from talking to young people with Down syndrome. He will be very careful not to put your name in the paper, or the name of anyone that you talked about. If you happen to mention the names of anyone in your interview, like other students, or teachers, their names will be changed in the paper. This is so you can feel comfortable talking about anything, and you don't have to worry about anyone being upset about what you said. The student researcher will never tell anyone that you took part in this study, and will save your interview data on a secure computer that nobody else will be able to see.

It is important for you to know that the only reason the student researcher would ever tell anyone something that you said would be if you told him that someone is hurting you, or you feel like you might hurt yourself or someone else.

**What happens if I change my mind and don't want to be interviewed?**

You don't have to do anything you don't want to, so if you want to stop and leave at any time, that's okay. Nobody will be upset.

**What are the Potential Benefits and Harms Associated with Participation in the Study?**

By talking about what you liked and didn't like about school, you can help to teach people how to make school a better place for students with Down syndrome. It might be hard sometimes to talk about bad memories, but these stories can help other students a lot. We will try very hard to make the interview a happy experience for you, because we don't want anyone to feel bad.

**Where do I get questions answered?**

Immediately following your interview, the student researcher will provide you with an oral and written debriefing of the purpose of the current study, and answer any questions that you might have. If you have any questions or comments at a later date, please don't hesitate to contact myself, Hugh MacDonald, (Graduate Student Researcher) by phone (xxx-xxx-xxxx) or email ([xxx@msvu.ca](mailto:xxx@msvu.ca)) or Dr. Mary Jane Harkins (Thesis Research Supervisor) by phone (xxx-xxx-xxxx) or email ([xxx@msvu.ca](mailto:xxx@msvu.ca)). If you have questions about how this study is being conducted and wish to speak with someone not involved in the study, you may contact the Chair of the University Research Ethics Board (UREB) c/o MSVU Research Office, at 457-6350 or via e-mail at [research@msvu.ca](mailto:research@msvu.ca).

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 Signature

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 Date

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 Parent/Guardian signature

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 Date



**Appendix B**  
**Invitation to Participate (Parent/Guardian participant)**

**Title of Research:** School experiences of individuals with Down syndrome: Issues surrounding inclusion

**Name of Researchers:** Hugh MacDonald, MA School Psychology student, Mount Saint Vincent University; Dr. Mary Jane Harkins, Department of Education, Mount Saint Vincent University

**What is the study about?**

We invite you to participate in a study exploring the experiences and perceptions of young people with Down syndrome in regards to their education.

**What will I be expected to do?**

Your participation is voluntary. If you choose to participate in the study, you will first sign an informed consent form, keeping one for your records. You will take part in an interview with the student researcher, Hugh MacDonald, in which you will be asked questions to direct your discussion of school experiences. Lengths of interviews may vary, but this likely will take roughly thirty minutes to one hour. Parents or guardians will also be asked to spend approximately 5-10 minutes completing a short demographic questionnaire about their child's curriculum history. You and your child will be asked to complete individual interviews, but by all means may be present for each other's interview if you wish. No individuals other than the student researcher will be present at the time of the interviews and confidentiality of responses will be closely guarded.

**Will anyone know what I said?**

Your name will not be attached to any of the responses you provide in terms of the paper-and-pencil questionnaires you complete or your interview data. Interviews will be recorded to aid in transcription and facilitate data analysis. A research assistant may help with the transcription, but your name will not be associated with the questionnaires or interview transcript and only the interviewer, Hugh MacDonald, will have knowledge of who was interviewed. Some quotes may be used from interviews in this study in presentations at formal research conferences and in manuscripts written and submitted for publication in scientific journals. All efforts will be made to insure that the participant cannot be identified from that material. Any names that come up in the course of the interviews will be changed to safeguard their anonymity. All data will be securely stored under pseudonyms on a private, password protected computer that no one but the student researcher will have access to. All audio files will be permanently erased following the successful defense of this thesis.

Please note that there are legal limits on information researchers can promise to keep confidential (e.g., child abuse and participants who may harm themselves or others). If any of these issues

were to arise during an interview, appropriate actions must be taken; however, given the line of questioning in the interview protocol, we do not anticipate these topics to come up.

**What happens if I change my mind and wish to withdraw?**

If you should wish to withdraw, just let me know at any time and you will be free to leave without penalty. If you choose to withdraw from the study, we will not use any of your data. If you would like to leave any items blank, you may do so without withdrawing from the study.

**What are the Potential Benefits and Harms Associated with Participation in the Study?**

A potential benefit of the study is to learn about how qualitative research is conducted. Further, you can know that your voice – your thoughts, perceptions, and experiences - are being sought as a way to build knowledge in a research area that has not been fully explored. A potential harm is that you may experience some minor discomfort when discussing negative school experiences. All efforts will be made to insure your comfort. If discomfort arises, it will likely be temporary and minor.

**Where do I get questions answered?**

Immediately following your interview, the student researcher will provide you with an oral and written debriefing of the purpose of the current study, and answer any questions that you might have. If you have any questions or comments at a later date, please don't hesitate to contact myself, Hugh MacDonald, (Graduate Student Researcher) by phone (xxx-xxx-xxxx) or email ([xxx@msvu.ca](mailto:xxx@msvu.ca)) or Dr. Mary Jane Harkins (Thesis Research Supervisor) by phone (xxx-xxx-xxxx) or email ([xxx@msvu.ca](mailto:xxx@msvu.ca)). If you have questions about how this study is being conducted and wish to speak with someone not involved in the study, you may contact the Chair of the University Research Ethics Board (UREB) c/o MSVU Research Office, at 457-6350 or via e-mail at [research@msvu.ca](mailto:research@msvu.ca).

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Parent/Guardian signature

\_\_\_\_\_  
Date



### Appendix C Consent Form

I have received a copy of the Invitation to Participate for the research project entitled, *School Experiences of Individuals With Down syndrome: Issues Surrounding Inclusion*, have had an opportunity to read the information provided or it has been explained to me, have understood the information, and have had any questions that I may have had answered. I am aware that I may also ask the researcher questions in the future.

I agree to participate in this research project, understanding that I am doing so voluntarily, that confidentiality will be maintained, and that I have the right to withdraw from the study at any point using the means outlined in the Invitation to Participate without penalty. Some quotes may be used from interviews in this study in presentations at formal research conferences and in manuscripts written and submitted for publication in scientific journals. All efforts will be made to insure that the participant cannot be identified from that material.

\_\_\_\_\_  
Participant Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Parent/Guardian Participant signature

\_\_\_\_\_  
Date

Please check one of the following:

Please send me a summary of the results at the end of the study

Do not send me a summary of the results at the end of the study

\_\_\_\_\_  
Email Address (to forward study results)

Researchers:

Hugh MacDonald  
MA School Psychology Student  
Mount Saint Vincent University



Dr. Mary Jane Harkins  
Department of Education  
Mount Saint Vincent University



**Appendix D  
Demographic Questionnaire**

**This section asks you to provide some *confidential and anonymous* background information about your child. Please answer the following questions as honestly as possible. If you are not completely sure of an answer, please choose the response that best describes your child.**

1. How old is your child? \_\_\_\_\_
2. Is your child male or female? \_\_\_\_\_
3. Does your child have a history of significant medical difficulties? If so, please specify?

4. Please describe your child’s highest level of education.

- Less than high school
- High School
- College or Trade School
- Some university
- University- Bachelor’s
- Graduate School- Masters Level
- Other (please specify) \_\_\_\_\_

5. In elementary school, was your child enrolled in the general curriculum?  Yes  No

If “No”, please specify:


6. In middle school, was your child enrolled in the general curriculum?  Yes  No

If “No”, please specify:


7. In high school, was your child enrolled in the general curriculum?  Yes  No

If "No", please specify:




**Appendix E**  
**Interview Protocol (Student Participant)**

*School Experiences of Individuals with Down syndrome: Issues Surrounding Inclusion*  
 QUALITATIVE INTERVIEW PROTOCOL

QUESTIONS TO BEGIN THE INTERVIEW: General feelings towards school

1. In general, did (do) you enjoy your time in school?

Probes:

- Did you like school more when you were a little kid, or when you got older? Why did you like that time more?
- What classes did (do) you like the most? Why did you like that class the most? Why? The least? Why?
- Did (do) you like to play any sports/drama/music at school? Why or why not?

QUESTIONS ABOUT DOWN SYNDROME: Perceptions

2. Can you tell me anything about Down syndrome?

Probes:

- Do you think students with Down syndrome usually like school? Why or why not?

3. I have friends with Down syndrome are very kind and very fun. Can you think of something good about Down syndrome?

Probes:

- Did (do) you ever feel misunderstood in school?
- What do you think most people think about Down syndrome?

QUESTIONS ABOUT HEALTH

4. When you were a little kid, did you have to see the doctor a lot? How about now?

Probes:

- What kind of health problems were the worst?
- Do you have to take any medicine?

5. Was (Is) there anything you couldn't (can't) do in school because you were (are) sick?

#### QUESTIONS ABOUT ACADEMICS

6. In school, most people have some subjects that they are very good at, and some subjects that they find harder. Did (do) you have a class that you were (are) really good at? Any that you found (find) harder?

Probes:

- How did (do) you usually feel when you got (get) your report card back? Why did (do) you feel that way?
- Were (Are) your parents usually happy with your grades? How did (does) that make you feel?

7. Now, just like most people have some classes that they really liked, and some classes that they didn't like so much, most people have some favorite teachers, and teachers that they didn't like so much. Did (Do) you have any favorite teachers?

Probes:

- Why did (do) you like that teacher?
- Were (Are) there any teachers you didn't like so much? Why not?

#### QUESTIONS ABOUT SOCIAL INTERACTIONS

8. Did you have many friends in school?

Probes:

- Were your friends in your class? In your grade?
- How often did you see your friends outside school?

9. Were there any students who weren't nice to you?

Probes:

- What did they say?
- What did they do?
- How did it make you feel when they weren't nice?
- Did you ever tell anyone about it, like your teacher or parents?



**Appendix F**  
**Interview Protocol (Parent/Guardian)**

*School Experiences of Individuals with Down syndrome: Issues Surrounding Inclusion*  
QUALITATIVE INTERVIEW PROTOCOL

QUESTIONS TO BEGIN THE INTERVIEW: General feelings towards school

10. In general, did (does) your child enjoy his/her time in school?

Probes:

- Did he/she enjoy school more in the earlier or later grades? Why do you think that was/is?
- What classes did (does) your child like the most? The least? Why?
- Did (does) your child take part in any extra-curricular activities (sports/drama/music?)

QUESTIONS ABOUT DOWN SYNDROME: Perceptions

11. Does your child have a good understanding of Down syndrome?

Probes:

- Has he/she ever asked questions about Down syndrome?
- Do you think students with Down syndrome usually like school? Why or why not?

12. Many people only think of the challenges associated with Down syndrome. Can you think of something good or positive about Down syndrome?

Probes:

- Do you think your child ever felt (feels) misunderstood in school?
- What do you think most people think about Down syndrome?

QUESTIONS ABOUT HEALTH

13. Did (or does) your child have any serious medical issues?

Probes:

- Have any health problems have affected your child's schooling?

14. Were (are) there any activities your child has not been able to participate in due to medical issues?

#### QUESTIONS ABOUT ACADEMICS

15. Did (does) your child have any favourite classes? Any classes your child did not enjoy?

Probes:

- Why do you think they enjoyed (didn't enjoy) that particular class?
- Was (is) your child usually happy with his/her report cards?
- Was (is) your child on an academic Individualized Program Plan?

16. Without naming any names, did (does) your child have any teachers they really like? Any that they really dislike? If so, why?

Probes:

- Did you ever experience difficulty with any teachers or administrators in regards to your child's education?

#### QUESTIONS ABOUT SOCIAL INTERACTIONS

17. Did (does) your child have many friends in school?

Probes:

- Were (Are) your child's friends in his/her class? In his/her grade?
- How often did (does) your child see his/her friends outside school?

18. Were (are) there any students who weren't nice to your child?

Probes:

- How did it make your child feel when they weren't nice?
- What did they say?
- What did they do?
- What was the school's reaction?

Final thoughts: Given that these interviews are aimed at helping us understand the school experiences of children with Down syndrome, are there any things that you think could be done differently to improve the experience for both parents and students?



### **Appendix G Debriefing Form**

Thank you for participating in this study. I greatly appreciate your time and effort.

The purpose of this study was to interview adolescents and young adults with Down syndrome, and their parents, about their school experiences. To do so, I reviewed available literature on this topic and other literature relevant to this study. I then developed a general interview protocol to follow within the interview. The protocol was designed to ask very open-ended or general questions, so that you, the participants, would be able to describe your perceptions and experiences in your own words.

This study was an exploratory and qualitative one. As such, no specific hypotheses were made. Rather, it was intended to hear about the perceptions and experiences of these students in their own words, develop ideas for further research questions and begin to develop theoretical understanding of the particular positive and negative experiences of students with Down syndrome in school. The questionnaire that parents completed following their interview will be used to describe the overall sample of participants included in this study in terms of their experience with mainstream or special classes.

Please note that all measures have been and will be taken to protect your confidentiality in this study. If you have any questions or concerns about participation in this study, you may contact Hugh MacDonald at xxx-xxx-xxxx, or xxx@msvu.ca.

If you would like a copy of the study results sent to you upon study completion, you can contact Hugh MacDonald and request that information.

Thank you again for your participation.