

## Qualitative Investigation of School-Related Issues Affecting Individuals Diagnosed with Autism Spectrum Disorder and Co-occurring Anxiety and/or Depression

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**Abstract:** This qualitative study investigated the experiences of adolescents and young adults (16 to 21 years old) diagnosed with an autism spectrum disorder (ASD) and co-occurring depression and/or anxiety disorders. The study was conducted with 9 parents of individuals with ASD and 4 individuals diagnosed with ASD and co-occurring anxiety and/or depression. The study used open-ended, online and face-to-face interviews and yielded rich data associated with a number of broad categories. This paper focuses on associated school-related issues; medical and initial diagnosis and community services. The participants provided valuable information about navigating school environments, programming needs, prevention of victimization, and mental health issues in individuals with ASD. The results suggest the need for mindful planning and programming for individuals diagnosed with ASD, as well as the need for awareness of the characteristics and programming associated with autism.

**Keywords:** ASD, anxiety, depression, school issues

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The co-occurrence of mental health issues associated with individuals diagnosed with ASD is well documented.<sup>1-7</sup> A Canadian study examining the incidence of clinically significant levels of anxiety and depression found that typically developing children have a rate of approximately 3% for anxiety and depressive disorders, while children diagnosed with ASD have a prevalence rate of 16.9% for depression and 13.6% for generalized anxiety disorders.<sup>5</sup> Gurney et al<sup>8</sup> found by analyzing a National Survey of Children's Health (2003–2004) a prevalence rate of 38.9% for depression and anxiety for individuals diagnosed with ASD compared to 4.2% in the general population.

Ghaziuddin et al<sup>2</sup> examining the phenomenology of depression and autism, suggested that depression is the most common co-occurring psychiatric illness in individuals with autistic disorder. They suggested that depression in individuals with ASD increases with age and may have 2 causal routes: environmental and/or genetic. Environmental causes may include stressors associated with family matters such as death or divorce,<sup>2</sup> or they may be associated with the individual's social problem-solving skills and past experiences of being teased.<sup>9</sup> As is seen in the general population, family history can be a significant factor associated with the onset of depression. Individuals with ASD who also have family members with histories of depression may be at increased risk of developing depression.<sup>2</sup>

The *Diagnostic and Statistical Manual of Mental Disorders* lists the common symptoms associated with depression as “poor appetite or overeating, insomnia or hypersomnia, low energy or fatigue, low self-esteem, poor concentration or difficulty making decisions, and feeling of hopelessness” (p. 380).<sup>10</sup> Ghaziuddin<sup>1</sup> suggested that symptoms of depression in individuals with ASD may present differently than they present in the neurotypical population. Ghaziuddin<sup>1</sup> reported increases in social withdrawal; oppositional behavior, aggression, and crying are more common symptoms for individuals diagnosed with ASD. As well, some individuals may shift their restricted interest to darker topics.<sup>11</sup> In individuals with ASD there are difficulties in obtaining an additional diagnosis, especially for individuals with communication skills deficits, and therefore they remain

underdiagnosed. The term diagnostic overshadowing has been discussed in the literature in relation to individuals diagnosed with low cognitive functioning, and it may play a role in the underdiagnosis of additional mental health issues in individuals diagnosed with ASD.<sup>12,13</sup>

Anxiety disorders encompass a variety of disorders including generalized anxiety disorder, panic disorder, social phobia, and separation anxiety disorder.<sup>10</sup> Symptoms of anxiety in typically developing individuals include excessive worries and generalized fear (of separation, harm, harm to others), and specific fears (of things, situations, or separations from significant others). In individuals with autistic disorder and Asperger's disorder the presentation of these symptoms may be atypical when compared to the general population. Individuals with ASD may be anxious both about things they enjoy and about things they do not enjoy. Often symptoms are associated with poor problem-solving skills and the inability to navigate the social world. As well, individuals with ASD often have associated sensory issues, which make many of them hypersensitive to stimuli in their environment. Tantum<sup>14</sup> reported that individuals with Asperger's disorder experience a significant degree of anxiety; however, it may be difficult for individuals to recognize these symptoms.

Children diagnosed with ASD represent a distinct group in the school system, and while they share common diagnostic features, they have diverse behaviors, cognitive and communication capacities, and educational needs.<sup>15</sup> Most, if not all, children and adolescents diagnosed under the umbrella of pervasive developmental disorders<sup>10</sup> require an Individual Education Plan to meet with academic, behavioral, and social success. Children with ASD can challenge even the best schools and the most prepared teachers. Therefore, while inclusion in the regular classroom setting is possible, it does require careful planning and specific training.<sup>16</sup>

Teacher knowledge of ASD impacts the success of students with ASD in the classroom. Teacher knowledge can inform classroom practices, classroom structure, and the use of evidence-based instruction.<sup>17</sup> As well, knowledge of the underlying developmental progression and characteristics of ASD can inform teachers about the appropriate methods of



discipline and provide an understanding of the child's behavior.<sup>17</sup>

By the same token, research has found that lack of knowledge contributes to inappropriate teaching practice,<sup>19</sup> inappropriate classroom structure,<sup>20</sup> inappropriate methods of discipline,<sup>21</sup> disciplining for characteristics of the disorder, and inappropriate interpretation of behavior.<sup>22</sup> Lack of knowledge also contributes to poor student–teacher relationships, placing the student with ASD at risk for teasing and bullying,<sup>15,23</sup> as well as increasing the student's risk for social isolation and behavioral difficulties.<sup>24</sup>

## Methodology

### Purpose

This project was intended to begin the task of exploring the experiences of individuals with ASD who developed a co-occurring depressive and/or anxiety disorder. The primary focus of the study was individuals diagnosed with ASD. However, information was gathered from 2 sources: 1 group comprising parents of individuals diagnosed with ASD and co-occurring mental health disorder; and a second group comprising individuals who themselves were diagnosed with ASD and co-occurring mental health disorder.

### Rationale

Currently, very little research has been conducted in which individuals with ASD are given a voice. Past research primarily focused on mental health issues including symptoms and experiences associated with typically developing individuals; consequently here is a lack of research that investigates the experiences of individuals diagnosed with ASD.<sup>12</sup> The current study contributes to our understanding of the issues facing adolescents and young adults diagnosed with ASD and co-existing mental health issues, specifically within the home and school environment.

At present, school-age individuals with ASD have the most contact with educational personnel. It has been documented that the behaviors associated with co-occurring mental health issues often go unrecognized both by educators and by physicians, or that the behaviors are assumed to be part of the disorder.<sup>2</sup> It is important for educators and primary health providers to understand the experiences of individuals with

ASD and to be alert to behavioral changes. While educators are not responsible for diagnosing mental health problems, they can certainly assist families in documenting behaviors and in helping them recognize when behavioral changes may be associated with the onset of a coexisting mental health disorder. Educators play a significant role in the lives of children with ASD and their families. They can be instrumental in recommending that families seek medical intervention and/or access treatment. The onset of mental health disorders for individuals diagnosed with ASD can further impair functioning and decrease the probability of positive outcomes in their future academic, social, and emotional development.<sup>2</sup>

### Context

This study took place in the province of Newfoundland and Labrador, which is a geographically large province with a relatively small population. Provincial statistics obtained from the Department of Education's website indicate that there are currently 484 students identified with ASD, another 102 students diagnosed with Asperger's disorder, and a further 130 students diagnosed with pervasive developmental disorder—not otherwise specified (<http://www.ed.gov.nl.ca/edu/FASTFT10.pdf>). The total provincial student population (K-12) for Newfoundland and Labrador is approximately 68,000 ([http://www.ed.gov.nl.ca/edu/publications/k12/stats/1011/g\\_SUP\\_10\\_6.pdf](http://www.ed.gov.nl.ca/edu/publications/k12/stats/1011/g_SUP_10_6.pdf)); the province does not have a registry for individuals diagnosed with ASD, and therefore statistics regarding the number of individuals outside the school system are currently unavailable.

This research study was designed using a qualitative framework in which the researcher sought to hear the voice of the participants and understand their individual stories as they attempt to make sense of them. As Smith<sup>25</sup> stated, “The participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant making sense of their personal and social world” (p. 40). Qualitative research produces descriptive or procedural knowledge; however, it also adds to our understanding the studied phenomena by giving a voice to individuals who have lived through a specific experience.<sup>26</sup> In essence, the researcher borrows other people's experiences, as well as their reflections



on those experiences, in order to learn from them. Phenomenology is a method of qualitative research that allows the researcher to go further in gaining an understanding of the lived experiences of the individual participants being studied. It allows the researcher to set aside preconceived ideas in order to understand the participants from their perspective.<sup>27</sup> The aim of the current study is to explore the details and understand how individuals diagnosed with ASD make sense of their experiences that led to an additional diagnosis of anxiety and/or depression.

## Participants

The individuals selected for this study were sought through advertisement. This was done in 2 ways: A letter introducing the study was sent both to the ASD consultants in the provincial Department of Education and to the Autism Society of Newfoundland and Labrador. However, all individuals who volunteered for this study were informed of the study by the Autism Society of Newfoundland and Labrador. The society has offices in a variety of communities throughout the province.

The sampling was “purposeful.” The individuals who participated had experiences with the phenomena of ASD and depression or anxiety.<sup>28,29</sup> The participants for this study came from a variety of urban and rural communities from across the island portion of Newfoundland and Labrador. The call for participants sought individuals and parents of individuals (not paired) diagnosed with ASD.

## Characteristics of individuals diagnosed with ASD

5 individuals diagnosed with ASD agreed to participate in this study. 2 individuals agreed to a face-to-face interview and 3 agreed to participate in an online interview. The researcher has assigned each of the participants a pseudonym. Some of the individuals have unique special interests; the actual special interests are removed from the direct quotes because those interests may allow them to be identified within the small community of individuals with ASD in the province.

**Sam.** Sam is a 21-year-old male who attended mainstream school. He currently lives at home with both his parents. He was diagnosed with Asperger’s before beginning school; however, his initial

diagnosis at age 4 years was social anxiety. He lives in an urban area, in a community of approximately 150,000 people. Sam quit school in January of his Grade 12 year, and shortly after quitting school he was diagnosed and hospitalized with a major depressive disorder with suicidal ideation. Sam participated in an online interview.

**Ryan.** Ryan is a 19-year-old male who attended mainstream school; he dropped out of school in Grade 10. He lives in a town of approximately 15,000 people, which is considered a midsize town for the province of Newfoundland and Labrador. Ryan moved out of his parents’ home this year and currently lives on his own but receives support services from community agencies. Ryan had extreme difficulty getting a diagnosis. He was initially diagnosed with a generalized anxiety disorder, then oppositional defiant disorder and social anxiety. Ryan did not receive a diagnosis of Asperger’s disorder until he was 15 years old. Ryan participated in an online interview.

**Jennifer.** Jennifer is an 18-year-old female who attended mainstream school. She lives at home with both her parents. Jennifer and her family live in a small rural community in Newfoundland that has a population of approximately 1,200 people. Jennifer is still attending school and is expected to graduate in another year. She was diagnosed with PPD–NOS at age 5 years. Jennifer was subsequently diagnosed with panic attacks when she was in Grade 10 (about age 15 years). Jennifer participated in a face-to-face interview.

**Dawson.** Dawson is a 19 year-old-male who attended mainstream school. He lives with his parents and his younger sister. Dawson and his family live in a rural community of approximately 5,000 people. He was diagnosed with Asperger’s disorder when he was approximately 7 years old; however, he was not informed of his diagnosis until he was about 13 years old. Dawson reported that he was also diagnosed with symptoms of obsessive–compulsive disorder when he was in Grade 5 and anxiety disorder when he was in Grade 7. He graduated from high school this year and has been experiencing ongoing mental health issues including 3 hospitalizations for suicidal ideation. Dawson participated in a face-to-face interview.

**Steven.** Steven is a 16-year-old male attending mainstream school and diagnosed with Asperger’s disorder. He lives with his parents and his older sister in an urban community. He is currently completing





Grade 11. Steven's online interview was eliminated from the data analysis because of a lack of information. His mother made the initial contact; she agreed to have her son participate, and he was also willing. They both signed the consent, and the initial e-mail was sent. Steven wrote, "school is hell for me." When I asked him, "Can you tell me more about that?" he responded with, "No, that pretty much sums up my life."

### Characteristics of parents of individuals diagnosed with ASD

The second group consisted of 10 parents (all mothers) of an adolescent or young adult diagnosed with ASD, with an additional diagnosis of depression and/or anxiety disorder (either current or past). The children of these parents consisted of 1 female and 8 males. The parents included in the study had children ranging in age from 15 years, 9 months to 21 years at the time they participated. Demographic information such as age, occupation, and education was not collected for the parents.

Within the parent group, 5 were parents of children diagnosed with Asperger's disorder and a coexisting anxiety disorder (pseudonyms Ashley, Anne, Alicia, Amanda, and Amy); 1 was a parent of a child diagnosed with PDD–NOS and coexisting anxiety disorder (pseudonym Paula). These children all attended mainstream school.

3 participants were parents of children diagnosed with ASD. (2 were still at school, and the third had just finished school at the time of the interview.) 2 of the participants were parents of individuals diagnosed with major depression (pseudonyms Darcy and Darlene) and 1 was the parent of an individual diagnosed with a generalized

anxiety disorder (pseudonym Denise). Their 3 children attended school in a special education setting. (These students would not be taught an alternative functional curriculum and not the province's prescribed curriculum).

In presenting the direct quotes for the themes, I will present the parent participants using their pseudonyms.

1 parental transcript was eliminated from the data analysis because the subject of the interview did not meet the second criteria of a co-occurring anxiety or depressive disorder and was also outside the age criteria set for this study.

### Methods

Recruitment letters were sent to the Department of Education and the Autism Society of Newfoundland and Labrador, which are both province-wide organizations. The advertisement provided potential participants with contact information including telephone numbers and e-mail addresses. The recruitment letter outlined the nature of the study, the types of participants, and the co-occurring diagnoses under study. During the initial negotiating phase, potential participants were provided with additional information on request. The purpose of the study was explained, and interview times were established. All who volunteered were interviewed. Ethical approval for the research was granted by Memorial University's Interdisciplinary Committee on Ethics in Human Research.

### Face-to-face procedures

1. For those who opted to participate in the face-to-face interviews, we negotiated via telephone or e-mail the date and time of the interview. The researcher travelled to various parts of the island

**Table 1.** Demographic information on parental participants.

Parent: pseudonym (gender)	Child's gender	Child's diagnosis	Child's age	Child's classroom
Darcy (female)	Son	Autistic disorder/major depression	17 years	Special education
Darlene (female)	Son	Autistic disorder/major depression	19 years	Special education
Denise (female)	Son	Autistic disorder/general anxiety	20 years	Special education
Ashley (female)	Son	Aspergers/anxiety disorder	16 years + 9 months	Mainstream
Anne (female)	Son	Aspergers/anxiety disorder	17 years	Mainstream
Alicia (female)	Son	Aspergers/panic disorder	17 years	Mainstream
Amanda (female)	Son	Aspergers/social anxiety	21 years	Mainstream
Amy (female)	Son	Aspergers/anxiety	19 years	Mainstream
Paula (female)	Daughter	PDD/generalized anxiety	18 years	Mainstream



portion of Newfoundland and Labrador to conduct the interviews. 2 interviews were conducted in the home of the participant; all others were conducted at public sites (Memorial University, St. John's, NL, and Grenfell Campus, Corner Brook, NL).

2. Before beginning the interview the researcher explained the process of informed consent. Each participant was given the opportunity to ask questions about the process, and they were required to sign the consent prior to beginning the interview.
3. The possible risks and benefits associated with discussing past events were reviewed as a part of the informed consent process, and participants were provided with information regarding places where they could seek help should the interview cause emotional distress.
4. Before beginning the audio taping, the researcher received permission from the participants to audio-tape. The researcher also asked permission to take notes during the interviews. The notes were mainly highlights of the interviews and areas that required clarification once the participants were done telling their stories. The researcher kept a reflective journal throughout the study (during both the data collection and the data analysis phases). These notes and reflections were also used as a part of the data analysis.
5. The researcher used an unstructured interview format to allow participants to have control over the information they shared during the interview process.<sup>38</sup> Once the consent was explained and signed, each participant was provided with the following beginning script:

[For parents] I would like to hear about your experiences with your child. You can choose how you want to go about telling about this, it's your experiences. You can talk about incidents or particular situations or you can start from the beginning and do a chronology for me. It is essentially up to you.

[For individuals] I am interested in learning about your experiences. You can choose how you want to go about doing this, it's your experience. You can tell me stories about you life or specific situations you've encountered. Essentially it's up to you.

6. The face-to-face interviews were 60 minutes to 90 minutes in duration; they were audio taped and transcribed verbatim. 7 of the interviews were transcribed by the administrative support division of

Memorial University, and the rest were transcribed by a graduate student employed by the researcher.

## Online interview procedures

1. All participants were offered the option of completing online or face-to-face interviews. 3 individuals participated in the online interview through the use of e-mail. The informed consent was sent via mail to the participants, along with a stamped, self-addressed envelope so participants could return the forms. They were required to sign the informed consent (along with their parents if they were under the age of 18 years) and return it to the researcher prior to participation.
2. Each participant was provided information about the study through an e-mail attachment. The researcher answered any questions participants had; if after their questions were answered they were still interested, they were asked to sign and return the consent. Once the consent was obtained, the following e-mail started the conversation:

I am interested in learning about your experiences. You can choose how you want to go about doing this, it's your experience. You can tell me stories about you life or specific situations you've encountered. Essentially it's up to you. I will read your response, and then I may ask you questions to clarify what you've written. Finally, once you've written everything that you want to tell me, then I will send you the series of e-mails for you to look at, add to, comment on, or change.

3. The online interviews occurred over a period of approximately 4 months; they were asynchronous interviews. Jowett, Peel, and Shaw (2011) suggested that online interviews allow researchers the ability to interview people from various geographical regions without incurring costs for travel. However, the rationale for online interviews in this study relates to 1 of the features of individuals diagnosed with ASD: difficulty with social interaction. This was not intended as a cost-saving measure, but as a means to allow individuals to participate without incurring the anxiety often associated with interacting with strangers. The main advantage for using online interviewing was to give individuals who would not agree to meet face-to-face the ability to tell their story.



4. Once the online interview was completed, the e-mails were transferred into a Word document and the Word document was sent back to the participants for feedback and correction. They were asked to read the document and to make any necessary corrections, to omit anything they didn't want included, and to provide any additional information.

## Analysis

1. The transcripts were checked against the original audio recording, either by the primary researcher or by the graduate research assistant hired for this project. Discrepancies were corrected, and the transcripts were forwarded either through mail or e-mail to the participants to check for accuracy. Feedback was provided to the researcher and any inaccuracies were corrected prior to the start of data analysis.
2. Each of the transcripts was read by the researcher and 1 research assistant in order to acquire a basic feel for the participants' descriptions, to "make sense" out of them, and to gain "closure or gestalt".<sup>25,30</sup>
3. The transcript for the first interview was coded by looking for key statements. Each of the key statements was then transferred into a word document. The key statements were then sorted into broad categories. The broad initial themes were: (a) medical/diagnosis, family (b) relationships, (c) peers, (d) school, and (e) community.
4. The data analysis for the first participant's transcript was completed prior to moving to the second participant's transcript. The above procedures were completed for each transcript and all transcripts were coded before cross-case analysis was completed to determine overlapping or shared experiences from the participants' own accounts.
5. The themes were validated by returning to the original data to determine whether anything in the transcripts had been missed and whether the cluster of themes suggested anything that was not implied in the original transcript.<sup>30</sup>
6. The participants within the study were asked to read the final themes to check for accuracy and credibility. The parents in this study were

forthcoming and provided valuable feedback on the themes; however, the individuals diagnosed with ASD did not provide feedback, even though several contacts were made with the participants to request feedback.

The researcher, therefore, used 2 individuals from outside the study to examine the themes and to check for their accuracy. Both individuals were above the age range to participate, but they had experience with the phenomena. 1 individual was a current graduate student with the Faculty of Education; she had a diagnosis of Asperger's and a coexisting diagnosis of major depression. The second individual was known to the researcher through her association with the Autism Society and was diagnosed with Asperger's and anxiety disorder. The information provided by these individuals was used in the final analysis. Creswell and Miller<sup>31</sup> described these procedures as methods for increasing the validity and credibility of the results.

## Findings and Discussion

Note that participants' statements are reported here exactly as provided or transcribed without further editing.

### Behavior intervention

All parent participants discussed significant difficulty with behavior associated with a school environment, an inability for their children to adapt to constant changes, and an inability to understand the expectations of the school environment. Most importantly, they identified that their children had significant problems navigating the social world of school. Parents reported that earlier intervention and a better match between interventions and the behavior (or the cause of the behavior) needs to occur within the school environment.

The parent participants felt that most school staff lacked an understanding of autism, of the behaviors associated with autism, and of the complex nature of autism, making intervention difficult. Parents generally felt that it is the school's responsibility to ensure that they provide a safe environment that meets the needs of all students. "Everyday I would get calls from school saying he was screaming and wasn't behaving properly." (Alicia)



Okay. It was a disaster. It's hard to know what to say. His special need was not accommodated. We had predictably bad results. When you treat an autistic spectrum child with an anxiety disorder like they are normal then you are going to get bad results. You are going to get a situation where the child does not cope well and acts out and does not learn, you know, that's what happened. (Ashley)

Parent participants in this study suggested that when interventions do not support change or behavioral adaptation, schools should look for alternative interventions. They believed behavior should be investigated through early assessment and appropriate interventions should be put in place based on that assessment. Several of the participants experienced having their children sent home regularly throughout their school career, yet the behaviors that caused their children to be sent home did not change. "I was working at [name of workplace] for 6 years before [name of child] started school. Then he went to kindergarten and the school kept calling me at work. Eventually I got fired [because] I was no longer reliable." (Amy)

I guess I'll start ... we could go right back to Kindergarten. I guess what happened was when he was in pre-school we'd be getting calls all the time that he wasn't behaving properly. He wasn't getting along with the other kids and so forth. And then, I thought, well, okay, he is just 4 years old but when he went to Kindergarten I was getting calls every day. Every day I would be getting calls from the school saying he was screaming out and he wasn't behaving properly, whatever. (Anne)

But at the same time his behavior in school became even worse. It was terrible. I used to be at work and I would be a wreck until 2:30 when I knew he would be out of school. At 2:30 I would relax if he had made it through the day without a phone call. I mean, up to 2:30 or so I would be waiting for a phone call saying he was freaking out or acting out with the other kids or whatever. (Anne)

They would remove him from the classroom but they would call us all the time. In Grade 1 and 2 there was a significant time we had to come and get him. A lot of the times as well though they would remove him from the classroom and they would call us and let us know that he was screaming and shouting and whatever he was doing. In junior high often we had to come and get him. (Amanda)

Parent participants saw removing the student with ASD from school as an easy way out for the school but essentially ineffective in dealing with the

underlying behavior. 1 participant stated: "So his behavior didn't get any better, he continued to scream and cry when school got too much and they would just send him home. They didn't know what to do but sending him home wasn't the right answer." (Amy).

The inability of teachers to deal with behavior had a negative impact on several of the participants included in this study. Parents reported having to reduce from full-time to part-time work, being let go from employment, or voluntarily quitting their jobs to enable them to be available to their school-age children. Participants also discussed the negative impact that behavior had on other family members, including added stress and resentment from parents, other children, or siblings. Most of the parents discussed a sense of being held responsible for their child's behavior and being blamed by the school system.

It was like this was my fault somehow I was raising a rotten kid and the implication was like "you're spoiling him" and that I was somehow a rotten parent. Well thankfully we'd been doing ok with [names the child] because I think I might have believed them. But you know what at home he was ok he was good with us. We knew some stuff to avoid and we did but I guess we just know him better. (Amy)

Participants discussed the need for school staff to have an in-depth understanding of behavior, appropriate classroom management, and structuring the school environment to accommodate behavioral and learning differences.

We have come a long way but we still have a lot of changes. I know some of this because I have been forced to learn because as a parent you tend to seek out and research stuff but more teachers wouldn't be aware .... Most teachers are just crying out for some practical strategies. (Paula)

Parent participants discussed the need to work together, to have an open and trustworthy relationship, and to be able to communicate regularly with one another. Participants felt that while they may not be teachers and they may not understand teaching methods, they often had an in-depth understanding of their own child. Many participants reported feeling that teachers presented themselves as "experts," and they did not provide an avenue for communication and parental involvement with school. Many participants took on adversarial roles with teachers and administration because the information provided





was ignored and the participants experienced school-based difficulty.

Parents know their kids. They know what works and what doesn't work and they can help teachers. I don't know why but so many want to reinvent the wheel or they just think they know it all because they've had other children with autism. Well that doesn't make them an expert in all children with autism, does it? (Ashley)

They really need to do more ... I don't know if they need to do more work, it's not as if they don't do enough now but, for my son, there is all kinds of information out there about it. Get information on it, understand what this child is going through, ask the child about what problems he has in the classroom, what bothers him. Actually, I was at an ISSP meeting last week and I did ask the other teachers, just the guidance counselor and the special education teacher there and the educational psychologist was there as well and I asked them if they are aware of what Asperger's is and so forth, and they said they weren't sure. (Anne)

Parent and youth participants felt that behavioral escalations interfered with the individual's relationships within the school environment, both teacher and peer. They felt that most of the time the onus was on them individually to adapt to the school environment even when they were often unable to adapt. Participants felt that a good understanding of ASD would assist school staff in understanding that it is not always possible for individuals with ASD to make the necessary changes, and that therefore the onus for change needs to be placed in the environment or with the adults responsible for creating the environment. This was particularly the case for individuals who experienced extreme sensory differences.

Individuals with ASD spoke less about behavior and more about their experiences. Of the 4 individuals who participated, only Jennifer received specific programming associated with social skills and anxiety management. Jennifer did, however, discuss difficulty navigating her social world even with this training. She stated she was not interested in the things her peers were interested in. She would often lecture her peers about dangers associated their activities (for example smoking), and she would become upset if they didn't listen. She also experienced difficulty when her peers used swear words.

"Well, going out more and partying and those types of things. I don't like that because all the dancing

makes me tired. Sometimes the music doesn't interest me." (Jennifer)

Jennifer reported that her parents intervened with the school system to ensure that her needs were met. Even though Jennifer had an individual plan in place that allowed her to leave the classroom when she became overwhelmed, her teachers would do something that would increase her anxiety, for example, blocking her from leaving.

Don't stop me and try to ask me, "Do you really need to go to the bathroom now or do you just" ... when I get up to go I need to go. Just let me go. So don't stand me in front of everyone and start saying "Are you okay?" Because talking to me when I am anxious would trigger panic. (Jennifer)

Jennifer discussed that at times little unexpected events could be enough to set her off on a panic attack. She stated that once when she received her high school schedule and there were unexpected blanks (free time) in her schedule, she experienced a panic attack.

Jennifer also reported that teachers did not know how to teach to her needs. She said that when teachers stood and lectured to her it sounded like "blab, blab, blab," and she experienced difficulty focusing. She stated that when teachers lectured, she would become overwhelmed. She called lectures "snooze and cruise," and when asked what that meant, she stated "BORING." Jennifer indicated that she prefers information that is given visually.

Dawson and Sam reported not receiving the accommodations that were outlined in their Individual Education Plan. They both described getting kicked out of class for making noise or for talking out during class. They discussed having difficulties with fine motor skills and how difficult it was for them to keep up with note-taking in class. Sam and Dawson also discussed experiencing difficulty with changes in routines and how difficult it was to navigate these on a daily basis.

One of my difficulties when I was going through school was fine motor so my writing was very, very slow. There was absolutely no way that I could write a test in normal time in a classroom. So, my testing ... I often had to write my test. But anyway, during that time I would do what the teacher wanted but it would become really upset because I didn't do so good. (Dawson)

"I was being punished. Punished because I spoke out in class. I speak, make noises, I do this all the



time and I get punished, I get put outside the class.” (Sam)

Sam reported that his teachers in elementary school were “excellent;” however, once he hit junior high school “all they saw was my disability.” He reported that his teachers made him write his exams even though he was supposed to have a scribe. He states, “I can tell what the answers to exams a lot easier if I have to write then they’re slower. Writing exams didn’t ever tell what I knew.” Sam also reported extreme difficulty working in groups and reported that he couldn’t focus or do any work. He would also be picked on by his peers during these times, and he would eventually get himself into trouble and get kicked out.

There was nothing but long, group activity, which is like “feeding me to the sharks” that kind of stuff was like that for me. I hated working in groups, just hated it but almost everyday there was group stuff. There was so much noise everyone talking at the same time and nothing but chaos. (Sam)

Sam also reported that teachers did not have much knowledge on certain topics (his special interest). He would get into arguments with the teacher, and he reported that 99% of the time it would turn out that he was right. Sam reported he would often get into trouble because he couldn’t let it go when he knew he was right, and he would be kicked out of classes often.

I remember being down in the science classes and this is another teacher who was clueless. A lot of times she’d correct me on something and she’d be wrong. I’d look it up or Google it and send it to her and she’d be wrong. In this [special interest] no one can stump me because I’ve spend lots of time studying [special interest]. (Sam)

Dawson (like Jennifer lecturing her peers about the dangers of smoking and not following the rules of school), discussed not understanding how other students could easily break the school rules and described his overwhelming need to get the students to comply. He discussed the need either to tell the teachers in an effort to get them to comply or to lecture the students about the rules.

Ryan did not receive a diagnosis until he was about 15 years old and he had already turned off of school. Ryan, however, had an extreme anxiety around the possibility that he would say the wrong thing and be teased by his peers. He also had extreme anxiety

about unexpected noise. He would attempt to cope by ignoring his peers and listening to his iPod (which wasn’t permitted in his school).

People with AS just have problems socially, and it’s confusing for us. Also the sensory piece of Asperger’s is a big part of it too ... there needs to be more awareness about it. I’d just tell teachers that we aren’t trying to be rude by listening to music or chewing gum. I’d tell people to stop being so narrow minded. (Ryan)

Ryan also experienced difficulty with his family relationships, including his relationship with his parents and his older sister. “It was an argument, I still have problems with my sister she resents the stress and problems that my behavior caused in my family especially when I caused problems at school.” Ryan reported that he preferred to be at home and knew the types of behavior that could get him kicked out of class, thereby increasing the risk of acting out, since that behavior was a means of getting him out of a situation he found difficult to navigate.

School was so hard for me especially the noise and just being around people and I was so perfectionist and wouldn’t interact unless I thought I could do it exactly right which wasn’t very often. No one helped me! (Ryan)

## Early identification of learning and sensory issues and use of appropriate accommodations

The parents participating in this study indicated it is important that schools use a proactive approach and anticipate learning issues. They felt that learning problems and sensory issues are common in individuals diagnosed with ASD, that these should be investigated early, and that interventions should be put in place to remediate the problem(s). Parent and youth participants reported that learning and sensory issues put their children or themselves at risk for academic problems, increased anxiety, behavioral difficulties, and school refusal and dropout.

So, when your child is in school they should know, be aware that this is a common learning problem for children with autism. We were told they can’t do assessments to find out why he was having problems learning because he’s too young they wouldn’t be appropriate. (Ashley)

Participants reported that it is important that school staff identify and intervene when there are associated



learning problems. They viewed this as the ideal; in reality most of the participants had a mixture of experiences that depended largely on the individual teacher and the school administration. However, participants reported that even when assessments were completed and accommodations recommended, they still had to fight for services and supports to be implemented. They found that they were put in a position of “constant vigilance” to ensure their children were given the proper accommodations.

It was a disaster. It’s hard to know what to say. His special needs were not accommodated. We had predictably bad results ... You are going to get a situation where the child does not cope well and acts out and does not learn, you know, that’s what happened. (Ashley)

Parents indicated that they felt educators could invest more time in getting to know their children and what works for them. Participants identified that it is important for teachers to understand how individual students learn and how to use their strengths to their advantage and for their overall success including academic and social functioning. Of note, parents of individuals with Asperger’s and PDD–NOS failed to graduate on time, and 2 dropped out of school prior to graduation even though it would appear they had sufficient intelligence to achieve academic success.

Several parents discussed the role of school administration or school leadership in influencing the school climate and the interventions for themselves or their children. Participants discussed how effective leadership made the lives of their children so much easier in the school context. They reported that leadership can help set the tone, enforce learning and behavioral accommodations, and promote an overall acceptance. However, participants also reported that it is the administration’s responsibility to ensure that they have the necessary knowledge and understanding of ASD and that their teachers are trained to meet the needs of the students they teach. If teachers do not know about autism, then it is the administration’s responsibility to ensure they gain the necessary knowledge and skills. “When you got a principal that says, okay, I’ll do this, the teacher seems to be more on board. I’d have to say that any time the principal has been good, the school has been good. It is very, very correlated, yes. I think it is because good principals hire good staff.” (Darlene)

Support from the immediate level of administration, like I said before, makes a huge difference. Having a responsive principal, you know, everything from tiny little things like shuffling classrooms so that the personalities mesh better to going higher to get resources, to get board people, supporting the teachers. I imagine if they have somebody to support their problems and concerns to whose responsive, who listens, and says, okay, here is what we are going to do about it. I think that the worst teachers are the defeated ones, the ones who don’t try because nothing is going to change. (Ashley)

Parents of the individuals diagnosed with autistic disorder also discussed learning needs. They reported that because their children had associated communication problems, they were viewed as “low functioning,” and therefore it was assumed that their children were “unable to learn.” Parents discussed the challenges they experienced in getting teachers to provide “academic challenges” to their children, and these parents felt that their children were not achieving their potential. Participants felt once their children were moved into alternative programming, little was done to assist them to achieve their potential.

I used to come over every day to pick him up and drop them off, every day. Every day I went in he was watching TV, everyday TV .... But a student assistant that I knew really well told me that he sat in front of the TV every day, that’s all he did. (Darcy)

Understanding individual sensory differences and finding the most appropriate instructional approach play a significant role in the success of individuals with ASD in the regular classroom. Participants in this study reported that most teachers did not understand sensory differences and the impact sensory differences made on the individual’s ability to cope with a school environment. All the parents of individuals diagnosed with high-functioning ASD or Asperger’s described sensory issues as having a major impact on their ability to function in the classroom and in the broader school environment. One parent reported:

Sound frequencies and, oh, a perfect example is, like many kids on that spectrum there, he can’t stand being touched. And he can’t stand having his stuff touched. So if you really want him to “go ballistic” come up to his desk and move his pen an inch. (Ashley)

If they are loud or anything in the classroom he shouts at them. Interestingly enough, he does at lunchtime what [name]



does is that he goes out with the special needs children to eat his lunch because for [name] to go to the cafeteria would be very stressful for him because it is so loud and so forth so he goes out with the special needs kids. (Anne)

Sensory functioning had a major impact on individuals' ability to cope within the school and community environment. Teachers' knowledge and understanding of the behavioral and sensory differences—and their ability to program for these differences—were major factors identified by the individuals who remained with their typical peers. Teachers who allowed students to take breaks from the classroom environment, those who structured their classroom, and those who accommodated differences were well respected among the parents and individuals in this study.

Jennifer was the only participant who did not specifically discuss sensory issues. She did discuss the need for routine and predictability. However, Jennifer discussed using scents like hand cream and sanitizing gels and listening to music to calm herself.

Sam, Dawson, and Ryan all discussed difficulty with noise and light. Dawson and Ryan also discussed how they disliked being in the hallways with other students; however, Dawson was the most descriptive. He stated that in Grade 7 he started having to change classes for each subject, and he couldn't control the amount of noise or when someone might bang into him. Dawson reported that when he was bumped or touched by someone, he had the sensation of "loosing that part of my body" and experienced an overwhelming sensation or need to get that part of his body back. This meant sometimes "I had to touch parts that touched me to get my body back; I can't explain it that's just the way it was." Touching others caused Dawson significant trouble, especially in junior high and high school. He reported that he didn't know how to explain this to his parents or his teachers. He was reported by his classmates and would get into significant trouble and then get sent home.

"It's hell. It would help if teachers realize a lot of sensory and social aspects of high school can directly impact the work in school. Very negatively in some cases, at least mine." (Ryan)

## Prevention of victimization

Participants in this study reported that prevention of social rejection and victimization is critical.

They felt that behavioral escalations increased the likelihood of social problems and peer rejection. Not only did behavioral escalation increase the risks for peer rejection, they reported, it also provided peers with information on how to further escalate behaviors in individuals with autism. Sometimes peers were found to capitalize on the individual differences associated with ASD and to become skilled at knowing how to escalate the behavior of individuals diagnosed with ASD.

"They would you know just nudge into him knowing it would bother him. He had no kind of filter so he would just blurt and the kids would constantly say stuff just to provoke him." (Ashley)

Participants also reported that some teachers viewed behavior as purposeful and an attempt to aggravate them personally. They reported that teachers need to understand that the behaviors associated with ASD are usually not personal, nor are they meant to be rude or obnoxious. They are most often associated with confusion about the social world or students' inability to modulate their sensory systems.

Parents discussed the unique features associated with ASD that set their children apart from typically developing students. They indicated that ASD awareness is an essential component of the education for teachers or staff working with individuals diagnosed with autism. These unique characteristics were reported to place students with ASD in an extremely high risk group for victimization. Participants in this study reported significant bullying at school by peers. Sometimes the victimization was based on some unique characteristics, for example anxiety around "the end of the world," "global warming," or "spiders;" difficulties associated with "having their possessions touched;" or other characteristics including unusual interests such as "vacuum clearers," "Yu-Gi-Oh cards," or "anime."

Participants believed that special care is required and intervention is essential to ensure students are able to understand and navigate the complex social world of school. However, the participants felt that teachers were not prepared, nor did they know how, to intervene to prevent victimization. Even though social skills development was recommended for the majority of the participants, very few participants were actually provided with social skills instruction





and intervention. Most interventions focused on academic weaknesses and not on alternative skills. Participants in this study felt that it is important that individuals with ASD be protected from victimization and went as far as to state that without protection, the general education classroom can be a dangerous place for a student with ASD to be. They suggested that individuals with ASD require specific social skills instruction and opportunities to practice social skills in a safe environment, as well as instruction and assistance in how to manage bullying.

The experiences of individuals in this study who remained in the general school population were less than positive. Participants reported that they or their children were victimized by peers and indirectly by teachers. While participants did not report that teachers were directly involved in bullying, they did report a lack of intervention from teachers when victimization by peers occurred. Participants viewed teachers' responses as critical, but reported that teachers were often not skilled at intervention and often stood by and did nothing, thus giving peers an implicit message that it was "okay" to aggravate the student diagnosed with autism. Some parents lamented that teachers needed to move outside of their curriculum guides and think about both social and self-esteem issues, and as 1 parents stated, "they need to be visionaries."

Those children who remained in the regular stream with typically developing peers experienced peer-related difficulties. The individuals felt that they lacked an understanding of the school environment; they often felt confused. 1 participant stated, "everything social was confusing to me;" another stated, "I always felt awkward and didn't know why."

However, the parents of individuals in the study who were diagnosed with autistic disorder did not perceive their children as being victimized or bullied; rather, they reported that their children were accepted within the school community. Of note, these students were all placed in "challenging needs" or self-contained classrooms for students who are considered in need of a totally different curriculum. As well, these students were more likely to have a high adult-to-student ratio and were less likely to be in the general school population without adult presence.

## Self-reports

Jennifer, Dawson, and Ryan do not attribute their mental health issues to their experiences. They did report being teased and made fun of. Dawson gave several examples of experiencing "joking" from his peers such as moving his things, hiding his gym clothing, turning the light out when he was using the bathroom, and, in 1 instance, being confronted in the bathroom and being called a "freak." While he accepted at face value they were "joking and kidding," he recognized that he didn't particularly like what was happening. In contrast, Ryan described just needing to stay out of their way and "off their [other students'] radar."

Sam reported that he was victimized by his peers and, in a couple of situations, indirectly by his teachers because they didn't intervene to help him. Sam reported experiencing nightmares and reliving the things that were done to him while at school. Sam has a special interest that set him apart because it was unusual. Sam also has many fears about the future and experienced students taunting him about his fear.

He reported he was once locked in the school bathroom by a group of boys and was told "to make friends with the school toilet." Sam indicated that he was called everything from a "freak" to a "fat slob" by his peers. He described being followed home from school and being taunted by his classmates about his special interest; he reported students surrounding him during break times, with teachers watching and not intervening. Sam explained that he was told by his parents to "ignore them," but didn't find that this actually worked. He reported his classmates would "only work harder" at getting him upset, and when he eventually got angry or physical with his peers, they would laugh and he would be the one in trouble.

"They would wait outside the bathroom door, I didn't like getting my sneakers [runners] dirty, and they would stomp on my sneakers." (Sam)

In grade 5, I think, kids surrounded me and tease me. Didn't matter where the playground, the classroom. The teachers knew and did nothing until I pushed or shoved. Then I would be the one in trouble and sent to the principal. (Sam)

## Prevention and early intervention with mental health

Some of the participants in this study were diagnosed with anxiety disorders prior to receiving the



diagnosis of ASD. However, several of the participants with the primary diagnosis of ASD reported that they were not aware of additional risks such as co-morbid depression and anxiety disorders associated with a diagnosis of autism. Participants reported that being aware of the risks could make a difference in seeking interventions to mediate the risks. Participants suggested that interventions such as anxiety management, social skills courses, and strategies to deal with bullying could potentially allow the individual with ASD to experience a better outcome and move through adolescence with their emotions and self-esteem preserved. “We are looking for strategies but one thing I would say, teachers, medical doctors, whatever, is to make parents aware of the strategies that could be out there.” (Amy)

Some of the participants expressed frustration that they were not informed about these risk factors, and, as with other facets of autism, were left to navigate the mental health issues associated with ASD on their own. The lack of information regarding the risks actually prevented families from seeking early intervention when their children started to exhibit behaviors that were out of character.

My child changed, he was no longer active, interested, or curious, all he wanted to do was sleep, he cried all the time. The teacher told us, “he’s coming out of his autism, improving” and maybe it was because he was less of a problem at school. (Darlene)

Parents of individuals diagnosed with ASD discussed the behavioral changes associated with the onset of depression; however, these symptoms were viewed by professionals involved with the individual as part of the “autism” and not the onset of a mental health difficulty. Parents looked to family doctors and teachers in an attempt to understand the behavior, and all were told by the professionals they consulted that it was “common behavior for adolescents.” Families viewed physicians and teachers as “experts” and listened to their advice. In hindsight, families commented that these professions should be educated, should have knowledge regarding the behavioral changes, and should have recognized them sooner instead of indicating that the behavior is a part of normal adolescence. The view that these children were entering normal adolescence actually prevented families from seeking help sooner and caused them

to second-guess themselves and their concerns. If instead, the onset of mental health issues had been brought to their attention, they could have sought intervention. The parents felt significant guilt for not seeking treatment earlier. “Everyone said including his teacher and doctor, ‘Oh, that is puberty, this is normal welcome to adolescences.’” (Denise)

2 parents and 2 individuals diagnosed with ASD discussed lasting effects, such as repeated nightmares and panic attacks, associated with their personal high school experience. These parents also reported that they believe the experiences of being bullied weighed heavily on their children’s minds, interfering with their ability to function at school as well as their mental health. “Your child is in so much pain and anguish he is saying ‘please shoot me, please kill me.’ I attribute part to what was happening in school because of the way he was treated, he was treated so ugly.” (Anne)

## Self-reports

Sam reported that no one recognized the signs and symptoms of depression until he attempted to cut his wrists. He said that he experienced increased aggression at home and school and found it much harder to cope at school. He began missing substantial amounts of school until he quit. He said he found it very hard to get out of bed, and when he was out of bed he craved junk food. He said he would eat so much he would throw up. He indicated that he was no longer interested in his favorite topic, was no longer interested in spending time with his family, and spent all of his time alone in his bedroom.

I came home [from school] and got down on the floor and I just cried and I swore and I said “I can’t go there [school] anymore.” Oh well, that was a horrible school, that was a terrible school and I don’t .... I am no longer going there now and everything and yet I have nightmares sometimes. (Sam)

Sam was in an academic program throughout his school career with help from the special education resource team. Sam reports that he was bullied at school—not during elementary, but once he started in junior high school. He indicated that other students would go out of their way to make fun of him, even students from the wider school community, students who were not in any of his classes. Sam reported that he feels his treatment at school directly impacted his



mental health and reported that if he had been protected from being bullied while at school he may not have had the serious mental health issues he experienced, including a suicide attempt. Sam reported that he continues to have dreams about the way he was treated in his school.

Dawson found that he had extreme difficulty being in the school environment. His sensory issues set him apart and increased his level of anxiety. He reported that the lack of predictability made school a very difficult place to be. Like Sam, Dawson experienced significant teasing from his peers. However, he accepted at face value when his peers said, “just kidding.” Dawson was diagnosed with an anxiety disorder in Grade 7, and he does not report any additional diagnoses; however, he was hospitalized for suicidal ideation at 3 points in his school career, once in Grade 10 and twice during his Grade 12 year. Dawson reported that he has always felt different and that he did not think he would ever be able to have any kind of life. “I see all the kids getting girl friends and boy friends and nothing for me, well not that I want a girlfriend yet.” (Dawson)

Dawson sees school as governed by a set of rules and can’t understand the students’ disregard for the rules. This has created a great deal of tension between Dawson and his peers, and he experienced extreme anxiety when other students disregarded rules.

Like swearing and smoking on school property. Don’t they get that it’s against school rules. Even though teacher and my parents tell me to “let it go” I just can’t I have to make it right and tell the teachers that so and so broke the rules. (Dawson)

This was similar to the experiences Jennifer reported. Jennifer also did not attribute her anxiety issues to her experiences. She reported that she had difficulty navigating the school environment and that minor things at school increased anxiety. Jennifer was also the only student who had any significant intervention. Jennifer reported feeling that schools should abide by school rules and regulations and that she needed to tell her peers what they are doing incorrectly.

Ryan was diagnosed with anxiety disorder before being diagnosed with Asperger’s. Ryan did not attribute his mental health issues to his school treatment, but he did indicate he believes that his teacher and doctor should have been better informed and more aware of what it’s like to have Asperger’s. He discussed his

belief that an earlier diagnosis could have helped his teacher, his parents, and his sister understand him better. He reported that his behavior has placed a great deal of stress on his relationships, and they still have not recovered.

## Conclusions

ASD is a complex disorder made more complex by the onset of mental health issues. This study is an attempt to understand the complex mechanisms that are associated with depression and anxiety by providing an “insider’s” view of what this might be like both from the individuals’ and from the parents’ perspectives.<sup>32</sup> In this study, interviews provided an in-depth look at the experiences of participants familiar with ASD and coexisting mental health disorders. By examining the interview data from this study a number of themes emerged; however, central to all themes was the importance of ASD awareness.

There is support in the literature for increased awareness, and Church et al<sup>33</sup> suggested that social skills deficits “remained the greatest life challenge” (p. 19). Specific problem areas need to be addressed, including behavior and sensory issues, to ensure the success of children. The behavior of individuals with ASD is often misinterpreted by those around them, and frustration and anxiety can sometimes increase the likelihood of inappropriate behavior.

The literature supports the notion that individuals with ASD present unique educational challenges.<sup>18,19</sup> As well, it is recognized that individuals with ASD are in a high-risk group for both mental health issues and peer victimization.<sup>5,34</sup> Therefore, there is a need for appropriate teaching methods, evidence-based behavioral intervention, and an emphasis on the prevention of academic and related learning problems, behavioral escalation, and social and peer relationship problems. It is important to provide early identification of learning and sensory issues and to adapt teaching and learning environments to the individual students. This would require that teachers and other educational personnel involved with the student invest time learning evidence-based practices, spending time both with families and with the individual students to determine the best approaches to learning and behavior. It would also require educators to develop skills for intervening with the associated difficulties such as social skills, navigation the social



world of school, and intervention to prevent teacher and peer victimization.

This study suggests the participants believe that teachers are not sufficiently trained to deal with learning, sensory issues, and behavioral challenges associated with autism. The lack of appropriate intervention puts the individuals at greater risk for peer rejection, academic problems, and other impacts on the individual's school career (such as school refusal and high school dropout).

There is also support in the literature indicating that children with ASD are at high risk to be bullied within the general classroom. Little<sup>35</sup> reported that 94% of mothers of individuals diagnosed with ASD reported peer victimization. Cappadocia et al<sup>36</sup> indicated that friendship and social difficulties place individuals with ASD at a greater risk than those in the general population. However, they also suggested that frequent victimization was related to the mental health issues associated with ASD. Little found similar results in her study and suggested that children with anxiety and sensory sensitivity (as well as other mental health issues) were rated by parents as experiencing more bullying.

Sterzing et al<sup>37</sup> in a nationally representative study for the US, reported that individuals with ASD are at higher risk to be victimized (46.3%), but they are also more likely to perpetrate bullying (14.8%). This study suggested that individuals with ASD may be both the victim and the perpetrator (8.9%).

The researcher does not intend to indicate a causal link between the experiences of individuals and their experiences with mental health issues, although some of the individuals reported this as a direct link. However, the researcher is suggesting caution because the onset of mental issues is a complex process for which blame cannot be placed in one area or the other.

### Limitation

The individuals and families who participated in this study were sought through advertisement, and all individuals who expressed an interest were accepted. The researcher did not formally screen for ASD but took parental or individual reports of the diagnosis at face value. As well, no other validating information

concerning the additional diagnosis of depression or anxiety disorders was sought, and the only requirement was participant report.

The themes derived in this paper were ones that were consistent across the participants; however, there was a broad range of individuals including: individuals with autistic disorder with and without verbal language; individuals with Asperger's disorder with a range of ability from average to superior; and individuals with PDD-NOS.

The small sample size does not allow generalizations to the general population of individuals diagnosed with ASD. The province of Newfoundland and Labrador is one with a history of economic hardship and of schools with limited resources and support. Therefore, the experiences may be unique.

### Author Contributions

Conceived and designed the experiments: SCP. Analyzed the data: SCP. Wrote the first draft of the manuscript: SCP. Contributed to the writing of the manuscript: SCP. Agree with manuscript results and conclusions: SCP. Jointly developed the structure and arguments for the paper: SCP. Made critical revisions and approved final version: SCP. All authors reviewed and approved of the final manuscript.

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Author(s) disclose no potential conflicts of interest.

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