Nothing About Us Without Us: Listening to the Stories of

School Experiences of Adults with Autism Spectrum Disorder

by

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Abstract

Students with autism spectrum disorders (ASD) should serve as a primary source of information when determining how to create supportive school environments. The purpose of this study is to listen to the voices of students with ASD to learn what conditions and practices support or undermine their achievement in schools. Based upon the premise that educators stand to gain from first-hand accounts, six adults with ASD from Winnipeg, Canada were interviewed about their lived experiences in schools. The stories were examined to discover aspects of the school environment that facilitated or hindered their social and academic progress. Results indicate that sensory demands, lack of friendships, bullying, unpredictability and lack of control are associated with undermining achievement, whereas compassionate peers and teachers, places for retreat and strengths-based approaches to working with students with ASD are supportive. Recommendations for educational practice to meet the needs of students with ASD are presented.

Dedication

This thesis is dedicated to the many children with whom I have been privileged to work

throughout my career. I believe that a truly great teacher nudges you down a path that you may

not have considered traveling otherwise. Thank you all for the nudges along my learning

journey. I also dedicate this to my family, who patiently took a backseat when this project asked

for my time and attention. You mean the world to me.

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Chapter One

A Critical Encounter

The oppressive heat during the month of June 2009 was extremely challenging to both

staff and students in the suburban elementary school in which I was working at the time as a

learning support teacher for Kindergarten through Grade Three classes. While we all longed

for the fresh air, warm sun and magnificent sense of freedom to explore the playground during

recess times, we were also very grateful for the luxury and relief of air conditioning as we

returned inside the school building, red-faced and hair plastered with sweat to our dripping

foreheads. It was during one of these scorching hot days that an educational assistant requested

that I escort the student with whom she worked on a daily basis, an eleven-year-old boy with

profound challenges related to a diagnosis of Autism Spectrum Disorder (ASD), outside during

the morning recess period. Given that I would be changing roles in the fall to work with older

students and eventually serving as this boy's learning support teacher as he entered Grade Six, I

welcomed this spontaneous opportunity to spend time with him and accepted her request without

hesitation.

A thick wall of searing heat met us as I accompanied Brett (a pseudonym) to the school

playground, an expansive grassy field surrounded by a chain link fence, with several openings to

the residential street and surrounding community. Knowing that Brett was nonverbal and prone

to bolting from school grounds, I stayed within arm's reach and gently guided him away from

the unfenced areas. Safety was of utmost importance, and my petite stature and build would be

no match for Brett's strength and determination should he feel the need to run from the enclosed

schoolyard.

It didn't take more than a few seconds before Brett began vocalizing a high-pitched siren-like sound and flapping his hands in front of his chest. This was nothing new; we were all used to this from Brett, as he exhibited these behaviours almost constantly at school, both indoors and out. I wasn't aware that there was any particular pattern to his sounds and actions, and assumed they were simply part of his daily repertoire. His eyes squeezed tightly shut, Brett continued the piercing vocalizations and made his way along the chain link fence, patting and stroking the warm metal with his fingertips and making a steady route of the boundaries of the playground area.

Suddenly, Brett stopped his movement and headed hastily towards a benched area close to the windows of his classroom. He peered inside briefly, then ran over a bench and ripped off his orange Crocs and grey socks so quickly that I had no opportunity to prevent it. Tossing the items onto the ground, he began rubbing the bare soles of his feet on the wooden seating of the bench. I watched, stayed close by and hoped that the wood was sufficiently worn and smooth that there would be no risk of slivers or other injury, however I certainly wasn't sure. Abruptly, Brett stood up, walked over to a shady area, peered in a window of one of the classrooms, and I listened as his vocalizations become louder and lower-pitched. Grabbing his socks and shoes, I heard the shrill sound of the bell signalling the end of recess and gently guided him by the wrist into the school, breathing a sigh of relief that Brett was safe and that we could escape the overbearing heat, which I suspected might be affecting him more than me.

Brett's vocalizations resumed their high pitch as we moved together into the cool hallway and towards the door of his classroom. Before I could react, he reached out and grabbed the neckline of my short-sleeved floral blouse and yanked, stretching it in such a way that I felt sure I was about to be disrobed. I shouted, "STOP!!" and he immediately let go. I could feel the

panicked thump of my quickening heartbeat and rush of adrenaline as I tried desperately to collect myself and follow Brett as he entered his classroom. In a deft movement, he took hold of the collar of his own T-shirt and ripped it, leaving a tattered edge. He then dashed to the corner of the classroom towards a worn, brown sofa on which sat one of his classmates, a slight girl, and immediately grabbed fistfuls of her long black hair in his hands. As she bowed her head in obvious pain and sobbed, the teacher rushed over and we feverishly worked together to pry Brett's fingers, one by one, away from her scalp and out of her thick dark hair as he clenched it with all his might. The educational assistant appeared, rushed over, and began to calmly stroke Brett's arm. As she guided him to a quiet area away from his peers, I checked with the teacher, who was consoling Brett's weeping classmate. As he nodded that all was under control, I left to return to my work in another classroom, replaying the incident in my head and taking deep breaths to calm myself. I was shaken and shocked by what had taken place, and felt that my years of experience and training as a classroom teacher and then as a learning support teacher had failed to help me respond appropriately to the situation. Although I had attained further education in the area of inclusive special education and obtained a post-baccalaureate diploma, this achievement bore no bearing on my ability to support Brett that morning.

In Pursuit of an Idea

This critical incident in my career marked the beginning of an interest and passion in learning about the educational experiences of individuals with ASD. Reflecting on Brett's experience with me that day caused me to pause and consider the vast implications of the incident on my own learning as a teacher and current school principal. It was certainly not Brett who had special needs in this instance; it was me, and there was a vast void in my knowledge and skills that needed to be addressed.

As I continued my work at school and came into contact with other students with ASD, the questions I considered steadily mounted. I observed behaviours that filled me with an insatiable desire to learn more about individuals with ASD and in particular, what I might learn and share with colleagues in order to improve our capacity to support their educational experiences. During the same period of time that my interest in this area was growing, a relative's rather precocious seven-year-old son was diagnosed with Asperger disorder ("high-functioning autism") and as I listened to the father's ongoing challenges as a parent and advocate for his son at school, my quest to learn became even more meaningful.

In searching for the answers to my ever-increasing questions, I sought information that could be obtained directly from individuals with ASD. This conscious intention was based upon the fact that I had become quite familiar with the views, opinions and recommendations provided by "experts" such as pediatricians, developmental psychologists and various researchers in the clinical and scientific field. I wanted to hear from Brett, and others like him. Fortunately, the availability of autobiographical literature and audio-visual materials authored and otherwise provided by individuals diagnosed with ASD has rapidly expanded in recent years.

The need to gain the ability to decipher and respond appropriately to the communicative attempts Brett's erratic behaviours were trying so desperately to convey to me during the incident on that hot summer afternoon inspired this research. What could I do differently to avoid an incident like this in the future, for Brett's sake as well as that of other students?   What do educators need to know to support students like Brett? What changes to practice and language are needed to hear and honour the voices of students who are rarely, if ever heard? What contributions may individuals with ASD have in deepening our understanding of how to provide an attuned, enriching and appropriate education?

Guiding Research Questions and Purpose

The intent of this research study was to contribute to an emerging body of research surrounding

the inclusion of the voices of individuals with ASD to our understandings. With increased

knowledge of how to best support students with ASD, we are in a better position to provide them

with an enriching and engaging school experience. This study also aimed to contribute to a body

of work seeking to empower, value and privilege the voices of people with ASD, who have for

too long had others speaking on their behalf.

The research questions to be examined were:

1) How do adults with ASD describe their social and academic experiences in schools?

2) How do adults with ASD describe the conditions and practices experienced in schools that supported or undermined their social and academic achievement?

3) What might educators learn from these first-hand accounts?

Chapter Two

Review of Literature

The evolution of our understanding and treatment of people with ASD reflects changes in knowledge and perspective that have shifted over time to shape our present-day approaches to working with affected individuals. Long before autism was formally identified in 1943 by Leo Kanner (Glynne-Owen, 2010) and Hans Asperger in 1944 (Wolff, 2004), in Germany, accounts of children with clinical features now considered to be characteristic of the disorder were documented in the medical literature of the era (Wolff, 2004). Once viewed as a psychiatric disorder and a form of childhood schizophrenia distinguished by profound "madness and melancholy" (Wolff, 2004, p. 202), our notions of ASD have expanded significantly. Over the last decade, there has been a perceivable shift from focusing solely on the medical-clinical-scientific interpretations of ASD towards considering the perspectives of parents as well as adults affected with the disorder (Davidson & Orsini, 2013). The authors suggest that new and emerging scholarship in the study of autism must involve a commitment to developing "new analytical frameworks using inclusive and nonreductive methodological and theoretical approaches to study the nature and culture of autism" and that research in the social sciences and humanities "demands sensitivity to the kaleidoscopic complexity of this highly individualized, relational (dis)order" (p. 12). The conscious and intentional inclusion of the first-hand experiences of people affected by ASD may have the potential to transform notions of autism and shift understandings and practices in many fields, including education.

An examination of key areas of the literature about ASD requires a close look at our current definitions and descriptions, as well as common therapeutic and educational approaches to intervention and treatment. What emerges from this examination is a number of areas of

controversy, many which cause us to pause and question what is still unknown and perhaps misunderstood. What is ultimately revealed is the need to adopt a critical approach to advance "new, enabling narratives of ASD that challenge the predominant (deficit-focused and degrading) constructions that influence public opinion, policy and popular culture" (Davidson & Orsini, 2013, p. 12) and which impact heavily upon practices in fields including education.

 While there is a wealth of research in the field of ASD, it has focused almost exclusively on identification and analysis of the deficits associated with it, as well as emphasis on designing and trialing interventions that promote "normal functioning" (Glynne-Owen, 2010). This work has been the pursuit of medical professionals, scientists and autism researchers and has prioritized the collection of quantitative data from empirical, experimental studies. In stark contrast, a critical approach takes into account the development of disability rights movements, which seek to give individuals with disabilities a voice (Glynne-Owen, 2010).   Recognizing that disability is a social construct influenced in large part by changing political, social and economic contexts (Biklen, 2000; Kim, 2012), such an approach seeks to counteract the marginalization, discrimination and disempowerment that have prevented people with disabilities from participating fully in discourse. The tenets of this approach can be found in the field of critical disability studies, which took root in the 1970s as disabled activists sought to have their ideas, opinions and lived experiences recognized, valued and privileged (Reaume, 2014). Since then, both activists and allies in the critical disability field have sought to overcome barriers which serve to label, minimize and exclude individuals from fully participating in aspects of society, including those barriers which exist in educational policy and practice.   Adopting this approach requires resisting a static conceptualization of disability and honouring the "different" (as opposed to "disabled") experiences of people who have struggled to be fully included in schools

and communities. If inclusive practice is the goal towards which we claim to work, creating

opportunities for individuals with ASD to express the complexity of their experiences is

paramount. Listening to and learning from individuals who share the lived experience of being

students and citizens in our schools and communities has the potential to challenge predominant

ideas that have heavily influenced opinion, policy and practices in fields including education.

Arguably it is these individuals who are best poised to comment on the success or failure of

policies, procedures and practices to which they have been subjected, and who may provide us

with information that will enable us to improve the outcomes and experiences for future

generations of students. However any effort to expand upon the notions embraced by critical

disability studies requires an examination of understandings of ASD which characterize common

discourse and practice.

Definition and Diagnosis

The medical-clinical-scientific establishment has dominated literature to the degree that

anyone searching for a definition of Autism Spectrum Disorder (ASD) is highly likely to learn

first and foremost of deficits and impairments associated with it. Narratives of autism as a tragic

disorder threatening children, families and society as a whole pervade reference materials of all

types. From this narrow perspective, ASD is currently understood as "a group of developmental

disabilities that can cause significant social, communication and behavioral challenges "(CDC,

2014a, p.1). Previously diagnosed separately under conditions known as Autistic Disorder,

Pervasive Developmental Disorder not otherwise specified (PDD-NOS), Childhood

Disintegrative Disorder and Asperger Syndrome, the umbrella term of ASD describes individuals

affected to varying degrees by difficulties with social communication and interaction, as well as

patterns of restricted and repetitive behaviour. ASD is currently defined according to *The*

Diagnostic and Statistical Manual of Mental Disorders (5th ed.; *DSM–5*; APA, 2013), the most

widely accepted nomenclature used by clinicians and researchers for the classification of mental

disorders.

Researchers, clinicians and health care providers, upon whose work this understanding

of ASD is based, describe their clients as exhibiting deficits in social-emotional reciprocity and

communication, such as failing to share their feelings with others and engaging in back-and-forth

conversation, and as possessing a limited capacity to expand upon their narrow preoccupations

and interests, including demonstrating extreme discomfort with changes to their routine (Levy,

Mandell & Schultz, 2009). The degree to which individuals with ASD are affected varies from

those who are profoundly challenged, unable to communicate verbally and demonstrate

aggression and self-injurious behaviours to those who are very mildly affected and who may

exhibit a degree of difficulty interpreting and understanding social norms (Bauman, 2010).

In addition to the aforementioned deficits associated with ASD, a number of

comorbidities have been identified, including increased incidence of epilepsy, sleep disturbances

and gastrointestinal problems. Psychiatric comorbidities such as Attention Deficit Hyperactivity

Disorder, anxiety and mood disorders are also recognized as occurring relatively frequently in

individuals with ASD (Anagnostou et al., 2014).

Most often diagnosed during childhood, the prevalence of ASD diagnoses is estimated to

have risen rapidly over the last decade. In the United States, the Centers for Disease Control and

Prevention estimate that one in 68 children was identified with ASD in 2010, which represents a

29 percent increase since 2008 and a 64 per cent rise since 2006 (CDC, 2014a). However, CDC

states that these data cannot distinguish between an increase due to expanded ability to diagnose

ASD and a true rise in prevalence. It is also reported that ASD affects 3-4 times as many boys as

girls, and that the underlying cause for this distinction currently remains unknown (Manning-Courtney et al., 2013). Although prevalence rates in Canada are not as closely monitored as they are in the U.S., a study by the National Epidemiologic Database for the Study of Autism in Canada estimated that in parts of the country, the average annual percent increases in prevalence ranged from 10-15% (Ouellette-Kuntz et al., 2014).

Viewed internationally, efforts to document rates of autism are not nearly as exhaustive as they are in North America. Kim (2012) has suggested that the reason for this discrepancy is that various cultures around the world interpret and view autism differently, arguing that disability is largely a socially constructed phenomenon. O'Dell, Rosqvist, Ortega, Brownlow and Orsini (2016) argue that "the academic/scientific production or knowledge about autism is firmly located within particular geographical contexts, which give rise to particular understandings of autism that have become treated as universal 'facts" (p. 170). I believe that this assertion is critically important. Adopting a critical disability theoretical framework, I feel that interrupting the current focus in North America on prevalence rates, deficits, impairments and treatments and prioritizing what we are actively doing to honour autism as a way of living and being, as valued and worthy as any other human experience, is crucial.

According to the literature to date, there is no definite established cause for ASD, although it is thought to involve a combination of genetic and environmental factors. Risks associated with vaccine exposure, environmental toxins and in utero infections have either been disproven or account for only a very small proportion of cases (Anagnostou et al., 2014). Diagnosis of ASD is primarily based upon observations of the number and severity of characteristic behaviours as per DSM-5 criteria (Manning-Courtney et al., 2013; Levy, Mandell & Schultz, 2009). Given that there is currently no blood test or alternative medical procedure for

diagnostic purposes, tools such as the Autism Diagnostic Interview-Revised (ADI-R), Childhood Autism Rating Scale 2 (CARS) and Autism Diagnostic Observation Schedule (ADOS) are most often administered by a team of personnel from multiple disciplines (e.g. primary care physician, speech-language pathology, occupational therapy) and supplemented with behavioural observations, historical information and parent feedback to establish a diagnosis of ASD (Falkmer, Anderson, Falkmer & Horlin, 2013) .

Intervention Approaches

With children as young as two years old being identified as having ASDs, it is generally believed by clinical researchers and medical personnel that intervention should begin as soon as possible after diagnosis in order to improve outcomes (Glynne-Owen, 2010). Given that there is no current treatment to ameliorate all symptoms of ASD, intervention methods attempt to address the core behavioural, developmental and educational needs of individuals. Treatments vary greatly in terms of effectiveness, cost and availability and thus the circumstances under which an individual with ASD may be living – for example, geographical location or financial means – may affect the ability to access a specific intervention. When considering any particular intervention, the potential risks and benefits, level of dysfunction and effect on the family of the child should all be carefully weighed, as well as ensuring informed parental consent, ongoing monitoring and communication with home and school (Hollander, Phillips & Yeh, 2003).

Pharmacological and medical approaches tend to treat comorbid symptoms which interfere with a child's daily functioning, such as attention difficulties, hyperactivity, affective challenges (e.g. anxiety, depression), aggression, irritability, sleep disruption, self-injurious behaviours and perseverative activities. Research suggests that certain antidepressant drugs, mood stabilizers and antipsychotic medications may be helpful in improving symptoms and may

serve as an effective adjunct to behavioural and developmental treatments (Levy et al., 2009). Some families also consider alternative and complementary medical treatments including specialized diets, supplements, immune therapies, gastrointestinal remedies, withholding immunizations and chelation (a method of removing heavy metals such as mercury or lead from the bloodstream), while others opt to try non-biological interventions such as energy medicine, natural products and manipulative, mind-based and body-based therapies. In a review of these techniques, sometimes referred to as integrative medical approaches, Levy and Hyman (2015) found evidence that some are ineffective, some have potentially unacceptable side effects and that others require much more study.

Trends in intervention for children with ASD during their early years have their roots in both psychology and science (Glynne-Owen, 2010). Some of these interventions are comprehensive in nature, while others focus on specific behaviours associated with ASD (Ospina et al., 2008). Contemporary intervention approaches tend to fall along a spectrum ranging from adult-directed, goal and task-centered models to child-focused methods where the child determines the pace and direction of the session (Hilton & Seal, 2007). Two of the most widely-recognized and researched comprehensive interventions are Applied Behaviour Analysis (Lovaas, 1987; McCeachin, Smith & Lovaas, 1993), and developmental social-pragmatic approaches known as Developmental Individual-difference Relationship-based Interventions (DIR) (Ospina et al., 2008). A third intervention, TEACCH (Treatment and Education of Autistic and related Communication handicapped Children) is designed specifically for use in schools.

Applied Behaviour Analysis, or ABA, is an approach based upon behaviourist principles of stimulus-response and differential reinforcement, and originated from research conducted

from 1970 and onwards by behavioural psychologist Ivor Lovaas at UCLA (Lovaas, 1987).

Simply stated, the goals of ABA are the reinforcement of desirable behaviours, such as speaking

and playing, and the extinction of undesirable ones, such as self-injurious behaviours. The

approach is founded upon the notion that intensive behavioural intervention involving young

children with ASD and the adults who play significant roles in their lives results in gains in areas

such as language, cognitive and adaptive skills (Lovaas, 1987). ABA, and other approaches

derived from principles of ABA intervention tend to share three common features: (a) one-to-one

teaching by adult tutors; (b) a discrete-trial reinforcement-based method, which entails the

systematic teaching of a desired response to a stimulus, rewarded by a motivating consequence

such as a small edible item; and (c) an intensive regime requiring up to 40 hours per week, in

some cases for three years in duration (Reed, Osborne & Corness, 2007). Applied Behaviour

Analysis interventions take place in multiple settings including home and school, and are often

supervised by board-certified behaviour analysts specializing in ASD (Anagnostou et al., 2014).

In a meta-analytic study of research into the effectiveness of ABA intervention, Virues-

Ortega (2010) found that "long-term, comprehensive ABA intervention leads to (positive)

medium to large effects in terms of intellectual functioning, language development and adaptive

behaviours of individuals with autism" (p.387). Despite these findings, ABA has long been

considered a highly controversial intervention, for reasons including its high costs, the intensity

of time and commitment required by the families of children undergoing the treatment, its

reliance on behaviourist principles of prompts, rewards and punishment, considered unethical by

many, and its ultimate focus on conformity (Ne'eman, 2010; Dawson & Gernsbacher, 2010;

Orsini & Smith, 2010; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013).

Developmental Individual-difference Relationship-based Interventions (DIR) are

approaches which involve the systematic identification of the functional developmental level of a child with ASD, taking into account individual differences in sensory needs and motor planning as well as relationships with caregivers significant in the child's life (Greenspan & Weider, 1999). Rather than focusing on specific skills or behaviours as in ABA, the DIR approach attempts to assist a child to progress to a more sophisticated level of development in terms of cognitive, communicative and social capacity by following the natural cues, emotions and interests of the child (NIMH, 2014). Children who have received DIR treatment have been reported to have made significant gains in emotional development and achieved reductions in patterns of restricted, repetitive behaviours (Liao, 2014). Controlled randomized studies of DIR approaches are extremely limited, however preliminary benefits cited from the available research include lower cost, a widely applicable "professional-as-consultant, parent-as-therapist" model and a greater focus on generalization of skills across settings and contexts (Pajareya & Nopmaneejumruslers, 2011; Solomon, Necheles, Nerch & Bruckman, 2007). As in ABA, DIR intervention places significant demands on parents to invest a great deal of time and commitment to the treatment and the focus lies in making children with ASD indistinguishable from their typically developing peers. When implemented in a school setting, both of these interventions require a significant number of trained staff in order to provide one-on-one interaction with individual children and adherence to program requirements.

TEACCH (Treatment and Education of Autistic and related Communication handicapped Children) is an educational intervention with four key components which consist of (a) modification of the classroom environment and the tailoring of activities to make them understandable to a child with ASD, (b) maximal use of the visual strengths of individuals, in order to supplement weaker skills in other areas of sensory development, (c) utilization of an

individual child's interests in order to design engaging and highly motivating activities, and (d)

support of self-initiated attempts by the child to communicate (Mesibov & Shea, 2010). A meta-

analysis of intervention studies assessing the effectiveness of the TEACCH program found that

the overall effect on areas of skill development (perceptual, motor, verbal, cognitive, adaptive,

social and maladaptive behaviours) was moderate (Virues-Ortega, 2013). It must be noted that

TEACCH typically takes place within the context of a segregated special education classroom,

with children with ASD educated apart from typically developing peers (Boyd et al., 2014). This

is a distinct disadvantage, particularly in countries where inclusion of students with special needs

is the norm and where the Salamanca Statement (UNESCO, 1994), which calls for education of

all children in inclusive settings regardless of differences, is respected both in policy as well as in

practice. While Italian researchers Panerai et al (2009) suggest that there is value to

incorporating elements of TEACCH in inclusive school settings, very little data exists and there

is great need for further research on the program's overall efficacy (Virues-Ortega, 2013).

Communication deficits tend to be a common characteristic of ASD, therefore children

are often deemed to benefit from specific speech-and-language interventions designed to

improve the frequency, form and function of expressive language (Paul, 2008). In educational

settings, these interventions also tend to fall along a continuum of highly structured, adult-

directed methods to those which are child-centered and make use of peer interaction in natural

settings. The use of occupational therapy is also frequently considered as a support, due to its

emphasis on facilitating sensory integration and building adaptive skills so that individuals'

overall daily functioning is improved. According to a study conducted by the Interactive Autism

Network (2009), occupational therapy ranks second to speech and language as the most

frequently provided services for people with ASD throughout the United States (as cited in

Tomchek, LaVesser & Watling, 2010).

Controversial Issues

Current understandings of ASD have evolved over time since it was first identified as a distinct psychiatric disorder in 1943. There remains a great deal of controversy surrounding the disorder itself and how it should or should not be addressed in diagnosed individuals. Given the lack of definitive information regarding its causes and origins, it follows that there is much debate around appropriate treatment and intervention (Bernier & Gerdts, 2010). This debate is made extremely complex by the fact that contributions come from diverse fields including psychology, pharmacology, sociology, anthropology, critical disability studies, neuroscience, medicine, education, and psychiatry. With rates of prevalence estimated to be increasing more than any other developmental disorder, topics of potential etiology and treatment have created intense debate in the research community, in the media, and among those with autism and their families (Davidson & Orsini, 2013).

Analysis of the primary sources of information about ASD shows that the dominant discourse has occurred almost exclusively within the medical-scientific-clinical arena (Pinchevski, 2005). A growing number of researchers are questioning the imbalance created when ASD is interpreted exclusively through the lens of a biomedical model, choosing to expand discourse to include the sociocultural contexts in which ASD is understood and viewed (Kim, 2012; Ashby & Causton-Theoharis, 2009; Biklen, 2000; Glynne-Owen, 2010, O'Dell et al., 2016). While the dominant biomedical model emphasizes ASD as a disability located within individuals and focuses public advocacy and effort upon "fixing" and "curing" these individuals through interventions and treatments, a sociocultural model places the focus upon the disabling and unsupportive elements of the environment in which individuals are expected to live and learn

(Davidson & Orsini, 2013).

Leading the way in challenging the medical-scientific-clinical views of ASD during the last decade and a half have been adults with ASD and the parent community (Langan, 2011). Not all individuals with ASD perceive their challenges as a disorder (Anagostou et al, 2014; Ashby & Causton-Theorharis, 2009; O'Neil, 2008). Indeed there is a growing number of researchers in the social sciences, humanities scholars, parents of children with ASD and adult members of the autistic community appealing to clinicians, researchers, medical professionals and other 'neurotypicals' (individuals without ASD) to expand their notions of ASD and situate autism within an abilities framework that respects the complex nature of individuals with the diagnosis. From the perspective of those who align themselves with the neurodiversity, or autism rights movement, ASD should not be seen as a disorder or a disease to be treated and cured, but as a different way of thinking, behaving, knowing and being, which should be valued and respected (Owren and Stenhammer, 2013). Proponents of this view point to strengths associated with an ASD diagnosis, including enhanced skills in some areas of perceptual reasoning, visual skills and memory function (O'Neil, 2008; Barnett, 2013; Stillman, 2003). British autism researcher Simon Baron-Cohen has suggested that referring to ASD as a condition (or "state of being") rather than a disorder is less harsh and stigmatizing, and acknowledges assets, deficits and a difference in cognitive style (2012).

Silverman (2008) has argued that pitting the biomedical and social models of ASD against one another in either/or terms is of little benefit to individuals with autism and that "the most successful studies are those that refuse to situate their claims firmly with one model or the other, but instead pay attention to the strategic uses of different models by various interested groups" (p. 336). Others call for a view of disability which acknowledges the need for support

and care for people significantly challenged by ASD and at the same time considers the perspectives, contributions and opportunities of self-advocates and other individuals with ASD who have chosen to communicate their viewpoints (Saverese & Saverese, 2010; Ne'eman, 2010). Billington (2006) suggests that adopting a "partnership" model incorporating the views and wishes of individuals with ASD with information gained from medical research involves a conscious effort to expand our thinking beyond a focus upon "lamely adhering to the mechanical traits of diagnostic criteria" (p. 11).

Regardless of these calls for changes in perspective, it is evident that these views remain in the minority, especially with regard to current policy and practice. Of the $22 million spent on autism research in 2008 in the United States, close to 80% was directed to causes, cures and remediation, whereas a scant 5% was allocated to questions surrounding services (Raymaker & Nicolaidis, 2010). Our schools are reflective of this current policy and practice. We continue to privilege psychological and special education approaches rather than looking to critical disability studies and narratives as we plan for students with ASD (Glynne-Owen, 2010). For example, a student with ASD is often referred to a school psychologist for a psychoeducational assessment as a first step when there are behavioural concerns in the classroom. There is little if any acknowledgment afforded to ideas of social perspectives of disability, neurodiversity or that there could be much less effort on training students to behave more like their classmates and instead much more emphasis on access and accommodation.

In addition to controversy about whether ASD should be considered a disorder, a difference, or something else altogether, there exists much debate surrounding the efficacy of behavioural and developmental interventions for addressing the core symptoms of ASD, as findings and interpretations are based upon a limited number of studies based upon weak

methodology, few participants and a lack of long-term follow-up (Ospina et al., 2008). Research into the efficacy of school-based interventions appears to suffer from similar limitations. A meta-analysis of research on the effectiveness of school-based interventions proposed that "restrictions in the research population, research settings, volume, scope, breadth, and comparability of the literature have restricted the capacity of research to contribute to significant progress in the debate regarding effective educational practices for students with an ASD in public schools" (de Bruin, Deppeler, Moore & Diamond, 2013).

Criticism leveled at the limited research in education goes far beyond the flaws in methodology. Authors point to the fact that it has focused almost exclusively on quantitative data gained from empirical, experimental studies (Glynne-Owen, 2010). Very little attention has been paid to consideration of qualitative analysis in this field, in which the voices of individuals living with ASD serve as a critical source of research data and contribute to our evolving conceptions and interpretations of the condition (Ashby & Causton-Theoharis, 2009).

Listening to Those with Autism

Carrington and Graham (2001) have emphasized the necessity for "more qualitative research in the field of autism to achieve an in-depth exploration of the real-life experiences of these individuals from their own perspective" (p. 48). Without autobiographical accounts as a means to expand current understandings of ASD and counter deficit-based constructions that dominate in professional discourse, there is a risk of furthering an incomplete frame of reference from which to plan and implement effective supports, services and programming. Without listening to the stories of students who have the experience of living with ASD, they will continue to be perceived as "the others", positioned as "lesser than" and lacking agency, power and privilege in our schools and society as a whole.

In order to explore ideas of competence and how individuals with ASD narrate their experiences in this area, Ashby and Causton-Theoharis (2009) analyzed the written accounts of authors with ASD and identified several factors considered to be supportive of the individuals' demonstration of competence within home environments. They then extended their findings to the context of school settings. These factors included the importance of broadening our conceptions of intelligence beyond test scores, building upon strengths and interests, providing structure and predictability as well as concrete objects to make connections to abstract concepts, and inclusion in classrooms with typically developing peers. In a similar vein, Biklen (2000) studied the works of disability studies scholars including those with ASD, autobiographies and students' commentaries and proposed that a number of lessons could be learned from them, such as "resisting static understandings of disability, creating and finding contexts for experiencing competence, learning to recognize and resist normate narratives of disability and honouring the experience of disability" (p. 337). These findings have far-reaching implications to consider when educating professionals and support service providers who may be working with individuals with ASD and their families.

Several small-scale studies have been conducted with middle and high school students on the autism spectrum in order to examine their lived experiences in schools in Australia, Singapore and the United Kingdom. These studies have identified difficulties with developing social relationships at school, primarily related to differences associated with a diagnosis of ASD (i.e. a limited range of interests, a need for routine, and communication difficulties), all which serve as a source of considerable stress and anxiety for the students (Carrington & Graham, 2001; Humphrey & Lewis, 2008; Poon et al., 2014). Other small-scale studies analyzing the school experiences of adolescents with ASD have concluded that their insights and perspectives

point to several school-based practices critical to effective educational experience, including environmental considerations, teacher characteristics and having support mechanisms in place (Biklen, 2000; Saggers, Hwang & Mercer, 2011).

The proliferation of autistic autobiographies (Grandin 1996; Hall, 2011; Higashida, 2013; Mukhopadhyay 2000; Stillman, 2003; Tammett, 2011; Williams 1992) also provide significant insight and enable a greater understanding by the neurotypical majority population of the everyday experience of individuals living with ASD.

Many autobiographical accounts describe unusual sensory sensitivities as a crucial aspect of the autistic experience, however there is no consensus on a "typical" pattern for all individuals affected. Mukhopadhyay (2003) and Stillman (2003) write of a world dominated by intense sounds, Tammet (2006) sees abstract objects in colour, and Grandin (1986) describes herself as thinking in pictures and as struggling with processing auditory input. What emerges is a need for caregivers and professionals to understand that "the sum total of such sensory sensitivities can be an intensely debilitating and assaultive experience, sometimes causing people excruciating pain" (Stillman, 2003, p. 94). In an essay entitled "All the Things I Have Ever Been", author Dawn Eddings Prince (2013) provides a harrowing account of these difficulties within the context of a school setting:

> A normal transition for the other children, the clanging of bells, the bright primary colors all around, the hard chairs facing one way, the smell of the other children, and even the smell of disapproval – all came to rest in my infinite body like arrows broken from the shaft or melted fragments too dangerous to remove. A smart child, I was so overwhelmed on a sensory level that all I could hope to do was make it through each day and then come home to crawl away into the forgiving wood or the darkness of my closet. (p. 323)

Author and poet Tito Mukhopadhyay, who was diagnosed with severe autism in early childhood and who has since gained the ability to communicate independently with the aid of technology, describes the agonizing experience of being observed by curious onlookers:

> I had no eye contact with anyone. But I could understand the glances from the other body languages which the person carried. I have read facts that autistics fail to understand body languages. Personally I am more sensitive to the attitudes of people. When I know that someone is watching me with curiosity, I feel uneasy. My body reacts to it immediately. I become hyperactive and flap my hands to release some of my stress. (p. 104)

From descriptions such as these, many involved in supporting people with ASD have come to understand the need to conduct individual observations, sensory profiles and environmental assessments to establish the steps necessary to provide relief and support to children with ASD in such scenarios. To cope with her particular difficulties, Grandin (1986) designed what she called a "squeeze machine" to provide firm, controlled pressure to her body and enable a sense of calm reintegration of her senses. Tinted glasses or coverings for fluorescent lights (to reduce visual stimulation), weighted vests and lap pads (to provide pressure) and noise reduction headsets and earbuds (to reduce auditory input) are all examples of contemporary tools and strategies considered by support service providers for use by students with ASD.

Autobiographical texts written by individuals with ASD also point to the importance of providing routines and predictability in an educational or home setting, as a means to reduce feelings of anxiety and fear associated with various types of change in the environment. Author Donna Williams (1992) writes of her school experience:

Though I could neither apply myself at school nor be told what to do, I was motivated, persistent, orderly, and systematic about that which might have held the attention of someone else for a few minutes at the most. It might have seemed that my world was upside down, but I needed consistency. The constant change of most things never seemed to give me any chance to prepare myself for them. Because of this I found pleasure and comfort in doing the same things over and over again. (p. 44)

A pervasive sense of fear dominates in a number of autobiographical accounts (Grandin, 1986; Williams, 1992; Barnett, 2013; Mukhopadhyay, 2003) and is aptly described in the following memoirs of Jerry, an adult with ASD whose recollections of his childhood provide a glimpse into a world characterized by terror:

His childhood experience could be summarized as consisting of two predominant experiential states: confusion and terror. The recurrent theme that ran through all of Jerry's recollections was that of living in a frightening world presenting painful stimuli that could not be mastered… he was also frightened of other children, fearing that they might hurt him in some way. He could never predict or understand their behavior. Elementary school was remembered as a horrifying experience. The classroom was total confusion and he always felt he "would go to pieces." (Bemporad, 1979, p. 192)

Reducing anxiety and fear within the classroom environment may be achieved through conscious and intentional planning. Strategies such as visual schedules (prominent pictures displayed to show the sequence of daily activities), visual timers to help students prepare for transitions and alleviate anxiety associated with time management, and creating classroom "cozy corners", or enclosed spaces such as small tents to which students may retreat when

overwhelmed, are all examples of practical techniques which have been developed with the help of knowledge gained from autistic experience.

First-hand accounts have also proven useful in providing information about the emotional consequences of sensory sensitivities and the heightened fear described by many individuals with ASD. In a qualitative analysis of several autobiographical narratives, Jones, Zahl and Huws (2010) proposed that the most common theme was that of a pervasive sense of alienation, which involves powerful reactions of feeling excluded and lonely. Indeed there is a common thread of alienism in the titles of many essays and books authored by people with ASD. Grandin has described herself as feeling like "an anthropologist on Mars" (Sacks, 1996), while author Jasmine Lee O'Neill entitled her autobiography "Through the Eyes of Aliens" (1998). In a book review published on the U.S. version of Amazon, Mukhopadhyay (2007) writes of the hurt he felt – more intense than his autism – when his behaviours were described by the author as "'beastly', 'alien being', 'possessed by a demon'" (para. 1).

In order to support individuals with ASD in the area of social-emotional health and positive self-image, it is suggested that they be recognized first as people with strengths and interests (Glynne-Owen, 2010; Saggers et al., 2011; Humphrey and Lewis, 2008; Carrington & Graham, 2001; Davidson, 2009; Stillman, 2003; Lanou, Hough & Powell, 2010). Capitalizing on students' authentic interests and strengths has been found to increase motivation and meet challenges in a variety of domains associated with a diagnosis of ASD (Lanou et al., 2010). In addition, educational support service providers such as autism consultants recommend the use of techniques including Social Behaviour Mapping (Winner, 2005), communication forms and self-regulation strategies. These techniques provide visual supports and prompts in order to increase students' self-awareness and promote healthy social-emotional development (E. Wainwright,

personal communication, February 18, 2014).

Despite recent gains in the quantity of literature honouring the voices of individuals with ASD, there remains a distinct scarcity of qualitative research taking into account the direct lived school experiences of individuals with ASD. Hacking (2009) suggests that "autism narratives are not just stories or histories, describing a given reality", but also serve to create "the language in which to describe the experience of autism and hence helping to forge the concepts in which to think autism" (p. 1467). The currently limited research base in this area is at extreme odds with the escalating number of students with ASD currently entering today's classrooms. Until the gap in the knowledge base is adequately addressed, students with ASD risk facing a number of barriers during their time in schools (Carrington & Graham, 2001; Humphrey & Lewis, 2008).

Theoretical Framework

Research in autism has been overwhelmingly guided by the Parsonian view of disability (Glynne-Owen, 2010). Parson believed that disabilities were illnesses defined by medical symptoms which impaired a person's physical and psychological abilities. Without the ability to perform tasks within a range or in a manner considered to be 'normal' for a human being, it was the responsibility of medicine and psychology to restore such individuals to 'normality' through medical or psychological interventions (Barnes & Sheldon, 2007). Studies based upon this paradigm are rooted in the positivist epistemology of knowledge, which asserts that objective, observable evidence and measurable data is the sole source of human knowledge. Assuming that that the only source of accurate knowledge about disabilities is gained through empirical, experimental research, the purpose of data gained as a result of research studies is to determine the most effective techniques for restoring 'normal' functioning in individuals with ASD (Glynn-Owen, 2010).

The emphasis on restoration or remediation of the inability within any particular individual to 'function' has a long history both in theory and practice. Thomas M. Skrtic, a pioneer in the field of disability studies, asserts that functionalism has shaped policy and practice in social professions including education for much of the twentieth and beginning of the twenty-first centuries (1995). Functionalism "assumes a single social reality to which humans react mechanistically" (Skrtic, 1995, p. 67). Within this paradigm, any social or human problem that might arise in a school setting can be attributed to a combination of two interrelated factors - inefficiency within the organization, and defective students. These problematic students, whose deviance from the norm is rooted "within the person, excluding from consideration causal factors that lie in social and political processes external to the individual" (Skrtic, 1995, p. 82), have been served for decades through approaches and practices based upon theory stemming from the disciplines of biology and psychology.

Because fields such as special education have their roots in these disciplines, methods and tools used in such fields have been founded in behaviourist theory and principles (e.g. Applied Behaviour Analysis) as well as in diagnostic and prescriptive teaching practices. Thomas and Loxley (2007) suggest that the notions of measuring ability and disability arose in scientific study in the past when "the instinct to separate seemed uncontentious and provided a rational basis for segregation" (p. 148). The problem inherent in such an approach is that "the professional models, practices and tools that flow from its functionalist assumptions, theories and metatheories have been shown to be ineffective at best and harmful at worst" (Skrtic, 1995, p. 87). The ineffectiveness and harm associated with traditional approaches like these have not only served to maintain the marginalization of students with disabilities. The focus on measurement of ability, diagnosis and categorization has also reinforced language and labels

which continue to devalue and disempower them. Thomas and Loxley (2007) articulate how labels help serve to shape negative and hostile interpretations of difference:

> There are certain social characteristics or roles deemed to be marginal, relative to the dominant norm structure that increases the probability of being given a label and hence moving towards a deviant career. More importantly, once the label has been attached – and this has to be done by an 'agent of social control' – for example, a judge, doctor, teacher, educational psychologist – it becomes part of an individual's status. Consequently, all other roles that an individual plays out become submerged under this status. (p. 91)

The authors proceed to encourage the deconstruction of traditional special education approaches based upon a functionalist mindset and the adoption of those approaches which "give back respect, identity and control to those inhabiting the institutions that we create for them" (Thomas & Loxley, 2007, p. 148).

Fortunately, the latter part of the twentieth and beginning of the twenty-first centuries have seen the emergence of a critical social model of disability which questions previous notions of causality, normality and the nature of the disabled experience (Barnes & Sheldon, 2007). The call for alternative methods of discourse which will better serve disabled populations, guide contemporary research and change devaluing language and practice has been embraced by an increasing number of scholars, advocates and activists. Within the critical disability studies movement, disability is viewed purely as a social construct and a form of oppression and power imbalance on a par with other forms of discrimination such as racism and sexism (Barnes & Sheldon, 2007).

Reaume (2014) proposes that critical disability studies "view disability as both a lived

reality in which the experiences of people with disabilities are central to interpreting their place

in the world, and as a social and political definition based on societal power relations" (p. 1248).

He voices the importance of accessing the experiences of disabled people from a mindset that

views them as experts in their own past and present. Ortega (2013) speaks of the emergence of

"critical autism studies", an exciting new field that "unlike the individualizing and depoliticizing

prevailing deficit narrative of autism, challenges the ways in which we think about notions of

diversity, normalcy and identity". Davidson and Orsini (2013) echo this proposal, calling for a

framework that "not only respects the complex personhood of autistic individuals but also

reveals how the negotiation of autistic identities holds important insights for how to view

normalcy and (cognitive) difference" (p. 13).

This paradigm shift calls for significant epistemological and methodological changes in

the way research is conducted. Rather than individuals with ASD viewed as objects to be

treated, controlled and normalized in order to become indistinguishable from the neurotypical

majority population, critical disability research aims to describe, interpret and ultimately

understand the multitude of experiences as a guiding framework towards the pursuit of social

justice for people with ASD. O'Dell et al (2016) point to the challenge for researchers working

within this theoretical framework to "take seriously commitments to scholarly inquiry that avoid

reproducing the hierarchical relations which govern research with so-called 'vulnerable

populations" and state that this requires "making a commitment to the meaningful involvement

in research of people with autism themselves" (p. 168). I situate my work within this context

and within the theoretical framework of those critical disability researchers who insist that

"disabled people must occupy meaningful, involved and participatory roles in the research

process" (Lawthom & Goodley, 2005, p. 423). The current study is intended to work towards

this pursuit of social justice by honouring the stories of autistic individuals as lived experiences worth studying and learning from. Critical disability research has the potential to lay the groundwork for embracing an alternative view of what it means to be autistic:

> Grant me the dignity of meeting me on my own terms – recognize that we are equally alien to each other, that my ways of being are not merely damaged versions of yours. Question your assumptions. Define your terms. Work with me to build more bridges between us. (Sinclair, 1992, p. 302)

Chapter Three

Method

This qualitative phenomenological inquiry aimed to add to the growing body of literature embracing 'insider' accounts as significantly contributing to our skills and knowledge (Billington, 2006; Carrington & Graham, 2001) and paving the way towards positive change and improved educational practice within schools.

Methodology

For the purposes of this study, a qualitative research method was selected, specifically a phenomenological approach, guided by a disability interpretive lens. As a researcher, I wanted to adopt a methodology that enabled a deep understanding of the lived experiences of individuals with ASD. Qualitative research uses interpretive frameworks that inform the study of social or human problems through "the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is both inductive and deductive and establishes patterns or themes" (Creswell, 2013, p. 44). The author goes on to state that conducting qualitative research facilitates the development of a complex, detailed understanding of the issue which can "only be established by talking directly with people, going to their homes or places of work, and allowing them to tell the stories unencumbered by what we expect to find or what we have read in the literature" (p. 480). My intention was to "empower individuals to share their stories, hear their voices, and minimize the power relationships" (Creswell, 2013, p. 48) between the participants and researcher.

Why a phenomenological study?

As Creswell (2013) states, "the type of problem best suited for this form of research is one in which it is important to understand several individuals' common or shared experiences of

a phenomenon… in order to develop practices or policies, or to develop a deeper understanding about the features of the phenomenon" (p.81). Phenomenological inquiry is ideally suited to educational research in many respects, especially in its primary premise that "humans are storytelling organisms who, individually and socially, lead storied lives" (Connelly & Clandinin, 1990, p.2).

A phenomenological approach to studying what it means to be autistic implies a conscious attention and effort to capture how things such as "school" are perceived and experienced by individuals. The task of the phenomenological research was to encapsulate the essence of what it means to be a student with ASD in an educational institution, and to achieve an understanding so as to approximate this perspective as closely as possible. By adopting this approach, it was acknowledged and assumed that reality is a socially constructed phenomenon and that the benefit of telling stories is that it is often a vehicle to discover what the social constructions are. Ferguson and Ferguson (1995) suggest that "what we mean by the term 'story' is simply one person's, or one group's, social construction of 'what happened'" (p. 109). A phenomenological study places the researcher in a position where the goal is to attempt to see things from other people's unique points of view in all their richness and complexity.

Although phenomenological research involving participants with ASD is scarce, Poon et al. (2014) point out that the inclusion of the voice of students on their perspectives of their school lives "can certainly contribute towards the understanding of their experiences from their subjective point of view as well as inform ways on how best to support and enhance their inclusion within their class and school communities" (p. 1070).

My research required keeping at the forefront the essential objective of collecting data without further marginalizing the participants, many of whom may have expressed past and

present vulnerability during the telling of their stories. Respecting the perspectives of participants, the sites in which they choose to share their stories, and maintaining a sensitivity to power imbalances during the research process were key elements in my approach to the research.

Why a disability interpretive lens?

Approaching the study using a disability interpretive lens entailed viewing ASD as an element of human difference and not as a defect. This was a crucial feature because this perspective needed to be reflected in the research process, in the kinds of questions asked of participants, in the language used, the appropriateness of communication methods, the manner in which the data was reported in a way that was respectful of power differences, and in how the study with ultimately benefited students with ASD.

Emphasizing description rather than intervention, the disability interpretive lens brings voice to those who may not often be asked to describe anything at all. Certain members within our society have likely had many more opportunities to tell their stories more often and to more people than have others (Ferguson & Ferguson, 1995). For example, university students are frequently asked to participate in studies and forums to gather their feedback, opinions and experiences. As an educator, I have countless occasions to share my stories with colleagues and others in a variety of contexts and settings. Hearing the stories of individuals with ASD "challenges inequity by legitimizing the perspective of those on the bottom of society as well as the top" (Ferguson & Ferguson, 1995, p. 107). It was my intention to listen to the stories of individuals with ASD in order to seek an understanding of their experiences from their perspectives, rather than from what I may have learned from my own personal and professional experience. In this respect, the real task was to discover the questions I *should* be asking, rather than what I was actually asking.

Iacono and Murray (2003) emphasize that "the researcher's responsibility is to demonstrate explicitly and in detail the value of the research, not only in terms of furthering the knowledge base, but, where possible, also in providing some positive outcomes for the participants" (p.49). Ultimately, the objective of this research was to set aside previously held notions and ideas and to listen to stories with the intention of developing an understanding of the lived experience of adults with ASD during their school careers, and ultimately how to make the school experience better for individuals with ASD in the future.

Design

During the study, I conducted one-to-one, open-ended, semi-structured interviews with six adults with ASD. Creswell (2013) contends that we undertake interviews when we want to "develop theories when partial or inadequate theories exist for certain populations and samples, or existing theories do not adequately capture the complexity of the problem we are examining" (p. 48). I connected with adults with ASD to record their stories of their school experiences. As the study progressed, I expected that the need for their stories to be heard would become more and more evident.

I felt that I was on somewhat new ground with this research focus; not a great deal of literature exists in the area of the school experiences of people with ASD, and within that literature, there is little documentation of the researcher also serving in a position of responsibility towards supporting the educational experiences of students exhibiting characteristics of ASD. I was poised to be able to use my privilege carefully and wisely in order to conduct research which had the potential to further the pursuit of social justice for autistic students. Sharing the findings of the study could inspire changes in language and practice and bring about positive change in schools.

Participants

For the purposes of this study, a call for volunteers was sent to six local/provincial associations. I was aware of the "need to protect vulnerable participant groups, while ensuring that demands placed on researchers are not so restrictive as to preclude valuable research" (Iacono & Murray, 2003, p.49) and therefore I approached the senior figures in these organizations and provided them with information about the study. A request to post about the study where potential participants would see it was made to the Autism Society Manitoba, Asperger Manitoba Inc., Manitoba Council for Exceptional Children, Abilities Manitoba, Open Access Resource Centre and Society for Manitobans with Disabilities (see Appendix A). The poster communicated details about the study and its requirements (see Appendix B). Interested parties contacted me directly by telephone or email to express their interest in taking part in the study.

In addition to the call for volunteers to the aforementioned associations, the research poster was made available to potential participants on Twitter and Facebook groups, including Manitoba ASN (Autism Self-advocacy Network). I intended to have six participants in the study, and to conclude all interviews within a 3-month time period. Participants were encouraged to bring a parent or other advocate with them if they chose, however the decision to participate in the research needed to be made autonomously by the participant prior to the interview.

If there was any doubt as to the capacity of a potential participant to provide informed consent, fully comprehend the study requirements and participate in the research without the risks outweighing the benefits, I intended to exclude the potential participant from my research. The issue of obtaining informed consent from vulnerable populations including those with

developmental disabilities has been the topic of debate for many years. The primary goals of informed consent are "to promote patient autonomy and self-determination through an exchange of pertinent information that allows making a decision based on a full understanding of potential risks and benefits" (Johnson-Greene, 2010, p. 145). The use of semi-structured interviews, an adapted consent form written in plain language format, and the option for participants to bring a parent or advocate with them should they choose combined to pose overall minimal risk. The use of a critical disability approach in the research study design, which respects autism as a way of knowing and being, also provided a level of respect that might not otherwise be present in a research study. Johnson-Greene (2010) has proposed that if the decisional capacity of the participant to provide informed remains in question despite precautionary measures such as these, a series of probing questions should be asked after reviewing the research protocol, including a query as to why the participant wishes to participate in the study. Inadequate responses to questions such as "what will happen if you decide not to be in this study?" would be seen as a sign that a prospective research participant might not be fully informed, and might be cause for exclusion from the study. Iacono and Murray (2003) suggest that determining people's capacity to provide informed consent to be part of a research study requires careful consideration, but that it is entirely possible that providing opportunities and invitations may actually increase their skills in making informed decisions. Ultimately it was my responsibility to be vigilant in ensuring adherence to ethical principles of research involving vulnerable participants.

The benefits to participants in this research included the advancement of knowledge in this area of study, the opportunity to learn about the research process, the potential to help future students enjoy a better experience at school and the opportunity to contribute to the growing

body of researching embracing an insider perspective. Being considered an expert on their

unique experiences and valued for sharing them for others to learn from was another expected

benefit.

It is important to note that the current diagnostic criteria for ASD merges Asperger disorder

into the ASD spectrum and eliminates it as a separate category (APA, 2014), which permitted

my research to include individuals identified with this diagnosis. The call for volunteers asked

for adults who: (a) had been diagnosed with or self-identified as having ASD; (b) were deemed

by the researcher to possess the necessary decisional capacity and communication capacity to

provide informed consent, to fully comprehend the requirements of the study, and to participate

in the research without risk to the participant; (c) had completed at least three years of formal

schooling in the province of Manitoba; (d) were willing to speak about the experiences they had

in school and the role of school in their social and academic development, and (e) were able to

spend between one and three hours being interviewed and engaging in follow-up member

checks.

Participants who responded to the study by email were provided with adapted consent

forms written in plain language (see Appendix C) informing them of the central purpose of the

study and the procedures to be used in data collection, the right to voluntarily withdraw from the

study at any time, the protection of the confidentiality of the respondents, the known risks

associated with participation in the study, and the expected benefits to accrue to the participants

in the study. Before each interview occurred, I reviewed the study requirements, clearly

explained the format and aims of the research study, clarified as needed, and ensured that

participants were willing to participate and aware of their rights.

A number of potential participants indicated an initial interest in participating in the study, however my efforts to schedule a date, time and location convenient to them were ultimately not successful. After several attempts to communicate my willingness to accommodate their schedules and propose new interview times went unanswered, I chose to stop further contact with three individuals. For this reason, the effort to recruit participants took longer than the anticipated 3-month time period. Instead, 5 months were needed for the recruitment process. In addition, the balance of female to male participation in the study was heavily weighted towards females, with 5 females and 1 male participant. Given reports that ASD affects 3-4 times as many boys as girls (Manning-Courtney et al., 2013), this aspect of gender imbalance in participation in the study was surprising to me.

Profiles of Participants

The six participants in the study varied in age from approximately 19 to 40 years. Five of the participants are women, and one is a man. Only one participant had received a formal diagnosis of ASD during the childhood; the rest had either self-diagnosed or had been diagnosed with ASD in adulthood. All participants were offered the option to choose a pseudonym or to have one assigned to them for the purposes of the study, and all except one opted to have me choose their pseudonym. The following profiles are intended to briefly describe the participants:

Violet.

Violet is a woman in her late twenties who is active in a local organization that advocates for support for people living with Asperger's. She currently works from her own home, which she recently purchased along with a boyfriend with whom she has been associated for several years. Violet worked previously for several years as a teacher in a rural setting within the province of Manitoba. She states that she was diagnosed with ASD in her late teen years and

that she continues to gain an understanding of her childhood and adolescence through her participation in autism advocacy groups. Violet was open in sharing how meeting with a therapist and learning as much as possible about ASD as possible have brought about self-awareness and helped her to come to terms with parts of her younger years that were particularly difficult to understand or resolve at the time.

Kelly-Ann.

Kelly-Ann is a woman in her late thirties who is married and who has two children. Both of Kelly-Ann's children have diagnoses of ASD as well. She is immensely proud of her children's achievements and gifts. Kelly-Ann is a stay-at-home mother and enthusiastic advocate for her children's education. She expressed multiple times how much she appreciated the opportunity to share her experiences and how important she felt my study was in furthering knowledge about the challenges students with ASD face in schools. Kelly-Ann did not self-diagnose with ASD until she was well into her adult years, and she expressed hope for future generations of students since she feels that there is greater awareness of the condition and the receptivity in school personnel to make accommodations to meet their needed.

Bailey.

Bailey is a university student in her early twenties who self-diagnosed her ASD several years ago. She was born and raised in a small community, however she had moved to live close to the university at which she is pursuing studies in the areas of human rights and disability studies. Bailey is the co-founder of a local autism self-advocacy group and embraces any opportunity to promote its cause. She and the other co-founder of the group met with me previous to her interview, as it was important to her to learn about my intentions as a researcher

before agreeing to participate in the study. Bailey is part of a close-knit family who she reports as supporting her advocacy work and her studies tremendously.

Marli.

Marli is an adult female completing additional years of high school with a focus on areas including life skills and job preparation. Marli lives at home with her family and has a baby brother as well as a sibling also attending the same high school as she does. Marli enjoys expressing herself through art and hopes to work as a merchandiser in the future. She has a keen memory for dates and has volunteered her time and effort at several local businesses as part of her job preparation classes. Marli elected to meet with me in an empty office at her high school and had the support of her teachers to facilitate a quiet setting for her interview. She eagerly showed me one of the classrooms in which her artwork is featured, after her interview concluded.

Pokémon.

Pokémon is a young man in his late teens who chose his own pseudonym. He lives at home with his mother, father and an older brother. Pokémon finished his high school studies recently and is now volunteering occasionally at a sports facility close to his home. He enjoys playing video games and watching sports, especially basketball and hockey. Pokémon chose to have his mother present during his interview, but was clear that he had much to share and that her involvement in the process was not necessary.

Carrie.

Carrie spent her first three years of schooling in a public school before telling her parents she did not want to continue attending. Respecting her decision, Carrie's parents homeschooled her until she entered university, although she participated in several high school classes through

distance education. She has an older sister with whom she is very close, and both are highly

accomplished students in their areas of study. Carrie is currently pursuing a medical degree after

achieving two previous university degrees in biochemistry and molecular biology. She stated

that she has two diagnoses in addition to ASD, including a severe learning disability. Carrie

articulated that she makes use of adaptive software which enables her to sequence her thoughts

and read material for her coursework. Upon the completion of her medical studies, Carrie hopes

to work as a neurologist with a sub-specialty in developmental disorders such as ASD.

Role of the Researcher

My previous experiences as a student, classroom teacher and learning support teacher and

current role as a school principal were not actively included and discussed as part of the

gathering of research data. This was intentional, as I was conscious of the potential effect that

this might have on participants. Ensuring a sense of equity and respect in our conversations was

of utmost importance to me. At no time did I want participants to feel that their voices were less

valuable or worth listening to than my own or anyone else's. In fact, I desired the opposite and

consciously conducted the interviews in a way that minimized my voice and placed the role of

expert exactly where I intended it to be – in the stories and experiences of individuals who had

lived and were living as individuals with ASD.

The role of school principal in particular may be interpreted as one of relative power and

authority, especially as compared with the role of student, however I was determined that this

potential interpretation not affect the study and therefore it was not featured in any respect.

Others, myself included, view the position of school principal as one of responsibility and

influence, and so it was with this in mind that interviews were conducted. Participants were

aware that my role was as a university student and as wishing to learn directly from them.

Listening to the stories of my participants provoked a great deal of reflection on the many experiences I had and currently have working with students with ASD. I am deeply indebted to participants for being open and willing to share their stories of school experiences with me. Their accounts of feeling socially isolated, anxious and fearful in an environment which is supposed to support learning caused me not only to reflect on what I might have done differently in previous situations with students, but also served to inform me on how to better support those students for whom I have influence during their current educational experiences.

Hearing about the demands of the school environment, many which are fairly easily adjusted, allowed me to propose changes which had an immediate positive effect on students at the school in which I work. In other cases, aspects of stories caused me to realize how much more there is to be learned, both personally and as someone in a position to be able to share my learning with colleagues.

Data Collection

For the purposes of this research, data was collected via semi-structured interviews and field notes. I prepared prompts (see Appendix D) of topical domains that related to situations specific to my research questions. Bogdan and Biklen (1998) believe that it is essential to build rapport as quickly as possible with participants to set them at ease and allow them to speak freely when asked questions. They also caution against making the participants feel as though they are being evaluated or judged. These objectives are considered as critical elements of the interview process and I was conscious of them throughout.

The interviews followed a semi-structured format and lasted approximately 60 minutes each. During the interviews, a voice recording device was used. The voice recordings were later transcribed. It is important to note that context, body language, and level of perceived

enthusiasm of the participants were also taken into account. While conducting the interviews, attention was paid to all of these areas as they solidified the fact that particular key words or phrases were the most significant part of what was being shared. These behaviours or physical changes were noted in my field notes. In this sense, my field notes were essential while transcribing the audio recordings. Notes were incorporated into the transcriptions and played an important role during data analysis. For instance, oral statements accompanied by relatively extreme physical gestures such as wincing or the hunching of shoulders were carefully noted and descriptors were included to accompany pertinent quotations in the results section.

A total of approximately 8.5 hours of interviewing took place during the data collection, and the interviews once transcribed comprised 107 pages of prose text data.

Data Analysis

Creswell (2013) provides a useful framework for data analysis of phenomenological research data, and recommendations he offers on this topic guided this portion of the study. The data collected was analyzed in a step-by-step process whereby data from the first and second research questions (interview transcripts and field notes) were systematically examined for significant statements, sentences or quotations that provided an understanding of how the participants experienced school as students. The examination involved a process of creating and organizing files for data, followed by reading through text, making margin notes and forming initial codes. Next the significant statements, sentences and quotations were analyzed and grouped into meaningful units and themes. Once these units and themes emerged, a textural description of what the participants experienced was written, and re-written.

Suspending judgment and previous understandings and choosing to adopt a stance of curiosity were important elements of the data analysis process. Given my experiences as a

student, teacher and current school principal, setting aside my personal understandings and biases was sometimes difficult. Adding discussion about the role of the researcher along with my personal experiences and the contexts in which they occurred was necessary in order to provide a more thorough and comprehensive description and a deeper understanding.

The final step of data analysis involved writing a descriptive passage which attempts to capture the common experiences of the participants and provide the essence of school experiences as described by the adults with ASD. A more holistic understanding, which approximates the deep, rich, complex and valuable perspective offered by these individuals' stories, was the goal of the passage.

The process of collecting data involved a continual need to return to my research questions and initial purpose in conducting the study. In this sense, it involved a cyclical procedure whereby continually reflecting on the results of one question-and-response cycle led to a more skilled and informed ability to conduct the next. It was imperative to evaluate and determine whether or not the right type of questions were being posed to elicit the responses needed to capture the full, rich experience of what these individuals saw, heard, felt and lived at school. I was also conscious that the focus throughout each interview needed to be on listening fully and without the goal of formulating the next question in my head. Fortunately, participants were relatively open and appeared in their body language and tone of voice to be comfortable sharing their experiences in a way that felt authentic and meaningful. The flow and length of conversation was indicative to me that many of these individuals had much to tell and many expressed appreciation at being offered the opportunity to be fully heard. On more than one occasion, an interview exceeded its expected duration because the participant had so much to share.

While it was tempting to consider and view each participant's experience as separate, distinct and unique to the individual, I felt it was crucial to discover what information linked each interview to the others and connected to the data set as a whole, in order to bring meaning and fullness to the perspective of these individuals. To be capable of articulating what was to be gained from listening to their stories, it would be necessary to pay attention to converging statements and ideas and respond in a way that would facilitate and uncover a more profound understanding. What was the connection between one experience and another? How was the school environment of this participant similar or different to that of this other participant? What characteristics of the school environment resulted in a participant or another feeling supported or not feeling supported? Were these characteristics in the school environment ones that could easily be modified?

As a researcher with a deep investment and interest in how the study might eventually impact the lives of future students living with ASD, it was challenging for me to determine when or even if this goal was achieved. I was constantly wondering whether or not a question posed slightly differently may have brought forward a richer response, and if the data I was collecting was relevant and sufficient in surfacing the very complex and nuanced reality of what was communicated to me.

The data analysis process required me to reflect upon the relationships between contexts and settings, participants' experiences and the connections between statements in specific stories. The following graphic is intended to illustrate my thought process as I sought to discover relationships between the data and research questions:

Figure 1. Interrelationships during data analysis process

As I began the process of data analysis, I created a file for each participant, consisting of the interview transcript and accompanying field notes. Working in a step-by-step manner, I systematically examined each file for significant words, statements, sentences or quotations directly related to the research questions. Re-reading each file multiple times and with thorough attention, time and detail was necessary in order to begin the process of interpretation. I endeavoured to immerse myself in the smallest of details, making notes in the margins and highlighting words, short phrases and key insights that arose as I read and re-read. I used a series of strings of letters to identify parts of files that connected to other parts within the same file. I then used these same strings of letters to connect similar stories and threads in other files. For example, multiple participants expressed in different ways a feeling of social isolation throughout their experiences in schools, which I labeled "SOIS" in the files. Using differently coloured highlighter pens and sticky notes, I worked and labeled files systematically to organize

them in a way that brought forward this aspect of their experiences as well as several other over-arching themes.

Further sorting, grouping and categorizing of comments and notes resulted in patterns and sub-themes within the over-arching theme structure. For example, under the umbrella theme of social isolation, which I chose to call "All by Myself", a sub-theme of bullying emerged as an important aspect in all but one file. Even the file which did not describe accounts of bullying referred to it indirectly. Given that the data sets were not overly large, this "hands-on" approach to managing the data and categorizing it worked well. Sticky notes were easily moved, sorted, grouped and categorized in order to synthesize the data in an efficient manner and allow pertinent themes to emerge.
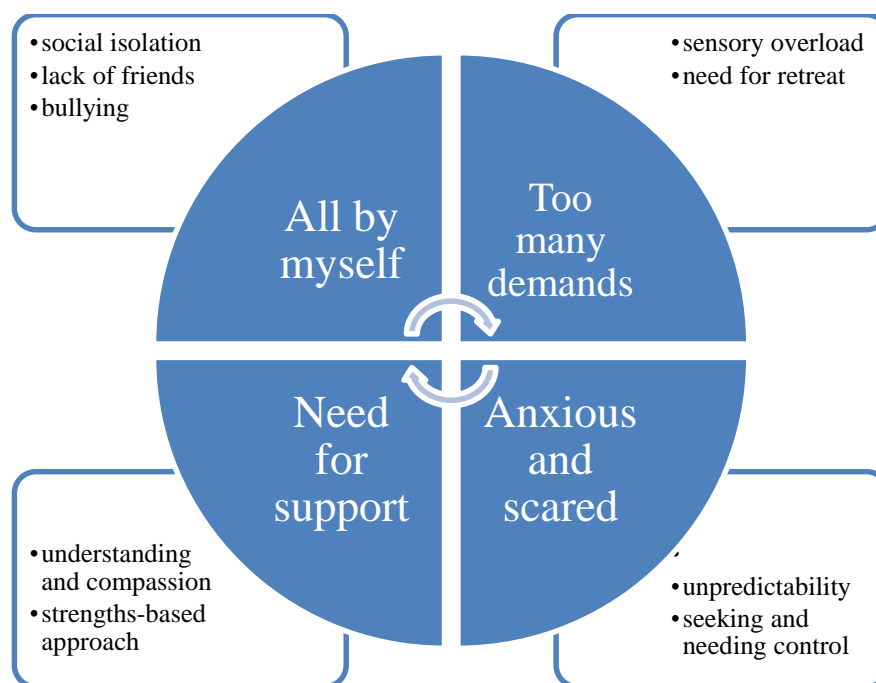
Chapter Four

Results

I conducted one-to-one, open-ended, semi-structured interviews with six adults with ASD over a 5-month period of time between June and November of 2016. These interviews, along with field notes formed the database from which themes were determined.

A distinct set of four themes and related sub-themes emerged from the interviews. They serve to capture the essence of what participants expressed about what they experienced in schools and what conditions and practices were perceived as supportive or counterproductive in school settings. The themes were:

- All by Myself

- Too Many Demands

- Anxious and Scared

- Need for Support

The relationships between these themes and their various sub-themes can be viewed in the following concept map. The non-linear aspect to the concept map is intentional, as the four themes which emerged from the data were very inter-connected and impacted upon each other in a constantly interrelated manner. There is a distinctly cyclical nature to the relationships between the themes. For example, coping with too many demands at school often caused feelings of anxiety for students with ASD. In turn, students coped with these feelings by seeking control of the topic of conversation with peers, resulting in social rejection. Together, these themes combine to provide a comprehensive account of the lived experiences of adults with ASD in the schools in which they were students. An exploration of the four themes follows.

Figure 2. Concept map of themes

- social isolation
- lack of friends
- bullying

- sensory overload
- need for retreat

All by myself

Too many demands

Need for support

Anxious and scared

- understanding and compassion
- strengths-based approach

- unpredictability
- seeking and needing control

Theme 1: All by myself

Recalling the feeling of living and being alone at school both physically and figuratively, even when surrounded by other students and staff, was a pervasive response from participants. Speaking frequently and sometimes quite emotionally about this, they described themselves as "social outcasts", "very distant from others", "so alone", "left out by everyone else", "completely on my own", "a loner", "being so secluded", and "different." The only participant who did not express this sentiment, Carrie, had left the school system after several years and been home-schooled by her parents until returning later for her post-secondary education. Otherwise there was a multitude of statements expressed by participants that revealed the depth of solitude they felt during their school experiences.

Three sub-themes related to feeling alone were social isolation, lack of friends and bullying.

Social isolation.

A sense of social isolation was clearly evident in one woman's explanation of being a "loner" during her years in high school. Violet stated, "You just feel so alone when you're on the spectrum. Why am I the only one who thinks like this? In the entire school… why am I the only one like this? And you just feel so incredibly lonely." Another participant, Bailey, verbalized her futile attempts to understand her social isolation, her hands outstretched as if in an appeal:

I didn't understand what was different about me. I assumed it was because I didn't get cultural references because I didn't have a TV. I thought everybody else was communicating through television and I couldn't do that. I assumed that was what it was, but of course I now realize that most people don't communicate through TV! It's likely that I was strange and different and kids don't like that. Lots of people don't like that.

Violet clasped her hands together and hunched her shoulders as if in pain as she recounted her aloneness during a year in elementary school:

I would just shut down. I remember feeling kind of left out by everyone else. They'd be in their little group by the teacher and there I'd be, all by myself. That's what I remember. Instead, you find a toy and play with it forever. I found a T-Rex. I was obsessed with dinosaurs for the longest time.

Whether the characteristic of social isolation was seen as negative or positive by participants was difficult to ascertain and even the same individual described it inconsistently.

For example, some participants articulated social isolation as a more natural aspect of their disposition rather than as a source of frustration to them. Carrie described herself as a "really quiet kid with a rich inner world". Bailey was in the process of pursuing post-secondary education in areas including human rights and disability studies, and she spoke of her social isolation in school in a more matter-of-fact manner, stating that she was "quiet and to herself a lot" and that during her early years in school she "would just take a book outside and sit under a tree and read". Kelly-Ann, a self-diagnosed woman with two children of her own, both with diagnoses of ASD, described a fond memory about a teacher in elementary school who had gone out of her way to accommodate Kelly-Ann's desire to work independently:

> She was the first teacher who actually took me under her wing and realized that whether it was bullying or something else, that I really, really, really wasn't doing good in group work. So she did things like… well, back then they didn't have E.A.s (educational assistants). She kind of was my E.A., she'd take me aside and work one-on-one with me. We had one where… where everybody had to do groups on different sea life, and mine was the jellyfish. I still have the report that I did. She allowed me to – and this is the story that I absolutely love – though we were supposed to do it in group work, she allowed me to do it by myself.

There appeared to be a conflict between a desire to be alone during certain situations and circumstances at school, and a desire for companionship at other times. Whether it caused frustration, a sense of relief, or other lingering feeling of living and being alone many years after these experiences actually took place, it was evident that participants felt that they spent much of their schooling in relative isolation. The sense of isolation was one that resonated in many stories

conveyed by participants, so much so that any reference to a connection to a specific peer or teacher seemed like an anomaly.

Lack of friends.

Lack of friendships emerged as a recollection shared by most. It was referred to often as a root cause of depression and anxiety at all levels of schooling. Kelly-Ann had endured a difficult schooling experience marked by a lack of connections with peers and the experience of being bullied. The following excerpt illustrates the suffering she endured at having no supportive friendships of her own in her younger years:

> Growing up in school was very, very difficult. People would tune me out because I would watch other girls… I'd watch other girls' mannerisms when they were around boys and I'd try to copy them, but it didn't come off right and the guys were running away from me. It was very frustrating to be able to maintain friendships and very frustrating to know, deep inside, that a lot of these people were pretending to be my friends because really, they were good friends with my older sister, not me.

Pokémon, a young man living at home, told several stories of frustrated attempts to make and maintain friends. One particular account of his lack of friends resulted in his voice breaking and trailing off multiple times as he attempted to convey the challenges he encountered during his years in high school. As he spoke, his head was lowered towards his chest, his shoulders hunched, and the hurt of this lived experience seemed etched in his body as it sunk further and further into the couch in which he was seated:

> I had some friends, but in high school I kind of lost…the hard part was probably losing my friends or not making friends and doing stuff…being so secluded or whatever. I

didn't have people to talk to…that's the hard part of it, because I had no…I guess the worst part of high school was not having friends or making friends. I was just so secluded.

Carrie spoke about how her challenges in this area as well, and how she suspected that a strong lisp may have also contributed to difficulty with friendships:

I couldn't talk clearly. I usually would have just one or two really good friends. As I got older, they tended to be a year or two younger, which I think makes sense because I was a bit of an immature kid. I would want to play dolls at eleven [years old].

The lack of friendships Violet had during her high school experience resulted in a feeling of low self-esteem that she felt contributed to an eventual diagnosis of depression in her early twenties:

Obviously they thought so little of me… when you're that young, you think, "I must be worthless" and you believe it. For so long and I think that's where the depression comes from. Not from your parents or your teachers, but from everyone your own age.

When asked if he had one good friend that he felt he could rely on during his years in school, Pokémon struggled to articulate his experience:

There were a couple, but when high school came I didn't really hang out with them anymore. And then I had tried, when I was in the room… but it just was hard… but once high school came, I just didn't hang out. Just left high school and that was it. I don't have anyone to depend on… not particularly, no. A couple of times I'd hang out with somebody, but it was usually just myself.

The difficulty of friendlessness in his school years marked much of the content of the stories told by this young man. Beyond the words he used to articulate this sad recollection, Pokémon's lethargic positioning on a couch and listless gestures as he spoke seemed to physically demonstrate the effect of lack of friendships on his self-image.

Bullying.

References to bullying permeated many of the stories and took many forms – physical bullying, verbal bullying and even inappropriate sexual contact in one case. Bailey recalled an incident when classmates in her elementary school invented a game in which "germs" were spread from her body to others by these classmates touching her when she wasn't looking. When she requested that the game stop, peers laughed and told her "it was really fun". Violet verbalized pervasive and ongoing name-calling during middle school. Her frustration at realizing that peers were only interested in communicating with her for their own benefit and not with an intent to create a genuine connection with her are painfully evident in her words:

> 'Geek', 'nerd', being left out. During class, if they had questions, they'd come to me. I'd explain it and as soon as the recess bell rang, they'd bugger off like I didn't exist. Okay, so obviously that was my place in the class. The go-to person for anything intellectual but as soon as they don't need that, I'm the scourge. There were kids who were smarter than me but for some reason they were popular and I wasn't. I was the nerd. It's such a long time ago but these things, they stay with you.

The theme of bullying was present in every participant's story of their school experience, aside from Carrie, who was homeschooled for the majority of her childhood and adolescence.

Despite not directly experiencing bullying herself, she spoke of her perception based upon some professional work she had been doing with children with ASD as part of her studies:

> Something that I never experienced and I mentioned earlier was bullying. I think that's a huge issue in the school system. I've heard some terrible statistics of bullying of kids on the autism spectrum… you hear these horror stories of people being bullied and it definitely does something to their confidence and it seems that they carry it for the rest of their lives.

Kelly-Ann's stories of being bullied at school recurred throughout her interview, and she spoke with much emotion, glancing down at the ground frequently and rubbing the tops of her thighs with her hands as we sat on a bench in a quiet public park together:

> I think being bullied as much as I was and knowing that it was because of… because of my Asperger's… really makes my heart go out to kids that struggle in school. It just… it wasn't fun. It led to a lot of physical bullying, emotional bullying, and I was also sexually abused by one girl growing up, and so it was just very traumatic for me.

The themes of feeling alone, without supportive peer connections and being bullied are particularly significant because one of the primary goals of schools is to provide an environment conducive to social-emotional development and learning. School is a location where many children and adolescents meet others with whom they develop life-long friendships and connections. High school reunions and similar life events which bring together adults who have shared school experiences are a common experience for many as people get older and go their separate ways in their personal and professional lives. What became clear through participants' stories was that interactions with peers were primarily characterized by negative experiences.

For individuals already facing many challenges related to living with ASD, it is evident that enduring social isolation and feeling as if they have no one to relate to created, for many, a long-lasting impact of frustration and enduring pain. As Violet verbalized, "There's nothing worse than feeling all alone and wondering what's wrong with you." If schools are committed to developing a culture and climate where every student feels as if she belongs, has supportive friends and is not alone in her daily struggles and challenges, there is much work to be done in this area as it relates to supporting students with ASD.

Theme 2: Too many demands

The demands presented by the physical environment of a school were a formidable challenge to participants. Factors such as noises, harsh fluorescent lighting and crowded spaces made school life hard for them. Pokémon, who explained that he continues to this day to avoid situations where large crowds are likely to be present, verbalized that "people too close to you… or just lots of people" are hard for him to tolerate. Others described "needing private space", "needing to breathe" and the ongoing quest to "find a quiet space" at school.

Two sub-themes related to the demanding school environment were sensory overload and the need for retreat.

Sensory overload.

Sensitivity to sensory information was a common characteristic of participants. What might not present a challenge to typically developing children, such as the buzz of overhead lighting, was articulated as being almost excruciatingly painful to some, and a common source of anxiety. The combination of sounds, textures, visual stimuli and odours created an environment so overwhelming in intensity that it provoked feelings of anger and frustration. Locations within the school building such as the cafeteria or gym were highlighted as particularly challenging.

Kelly-Ann, reflecting on the aspects of school she found to be particularly difficult, articulated her hatred of the gymnasium setting during physical education classes:

> Oh gee. I hated gym class! I hated gym because it was too… it was always too loud. You're running around sort of getting sweaty, and I hate being sweaty because it just makes me uncomfortable and makes me itchy… so yeah, the gym class was very, very hard.

Marli, a high school student completing extra years beyond what is typical for individuals her age, verbalized that she is very fearful of the "loud popping of balloons when tampered with". She mentioned class parties and special events at school as occasions where balloons might be present. Other participants articulated a more general sensitivity to auditory input. Carrie stated that she "just couldn't tune out sounds very much". During my interview with her, she requested that we meet early on a Sunday morning in an empty building on a university campus so that she would be able to focus without the challenge of auditory interference. The quiet setting accommodated her sensitivity and underlined the impact of her physiological need on her ability to function well. Being schooled by her parents at home had met this need for many years, allowing her time to develop strategies to cope with it later in life. She was now pursuing a medical degree after successfully gaining a Bachelor's degree in biochemistry and a Master's of Science with specialization in molecular biology. The fact that she lives with ASD was far overshadowed by her accomplishments.

Sensitivity to sound when also accompanied by the unpredictable and often chaotic movement of peers during regularly scheduled school activities such as recess were cited as very challenging. Bailey aptly expressed this:

I would have liked if recess was optional. I could have stayed inside and read. I understand that the teacher needs a break too, but it would have been nice to be allowed to sit there. It's also that inside has chairs and outside you have to sit on the ground! There's lots of people running around… and the sun's really very bright. Why couldn't I sit inside and read? One time I stayed in and organized book shelves at recess. That was cool.

Being constantly bombarded with sensory information and experiencing it more intensely than others do, school is a world that pushes students with ASD to states characterized by high stress. Bailey wondered aloud if sitting through her classes in high school was challenging because she "may have experienced it more intensely than other people did… because autism amplifies everything". Kelly-Ann articulated that modern-day items regularly found in school washrooms, such as "those stupid hand-dryers" and "self-flushing toilets" are a source of anxiety for her school-aged children living with ASD. Violet, who has been helped in recent years by learning as much as she can about the chronic state of anxiety in which she lives on a daily basis, articulated in detail the reality of her lived experience in a typical classroom setting:

At school, you have lots of stimulus and lots of stress… this kid who's listening to the chair behind him or her squeaking, and the person behind is doing this thumping sound, and the light is flashing. To them, it's perfectly normal to freak out because they've gone to fight or flight mode and they scream. The teacher is like, "What the heck just happened?" and now this is a problem child. I've always felt, especially during school… why is everything bugging me so much? Like why am I noticing these things and nobody else seems to notice? It's 3000 degrees in this classroom. Why is nobody else bothered?

There's a tile squeaking over in the left side, or the carpet pattern is hideous. Ew! It's

horrible.

While the sensory information in a typical classroom setting might not be problematic for

the majority of students taught within it, it was evident from many of the stories told by

participants that the assault of noises, sights, odours and textures provided considerable

challenge to their ability to cope and may well have been counterproductive to experiencing

social and academic success.

The need for retreat.

Stories of intense and often unbearable school spaces were accompanied by tales of

accommodating people and places, or of a wish to see more of the latter in schools. Places to

retreat to when students were anxious and overwhelmed, or to prevent them from reaching this

level, were spoken about frequently. Marli verbalized that "when things are not good, I need

private space" and that allowing her to put music on in the background as she works helps her to

concentrate. Carrie echoed that one of the issues she encounters frequently at the university she

attends is finding quiet spaces.

Bailey smiled as she talked about the comfort of a space provided by a teacher whose

classroom provided a quiet space away from the sounds and commotion of the high school

cafeteria at lunchtime:

There was this one teacher who always had puzzles in his room. At lunch I would go and

do puzzles. If I needed a place to go that was away from people, I would go do puzzles

and he would play classic rock from the speakers and there were posters of Star Trek and

Ghostbusters. And the lights were usually off. Anyone could go, but I was the only one

who did. It was a place to recharge if I wanted to.

Kelly-Ann spoke with pride about differences between her own school experiences and

those of her young children, describing that her son "does better when he's not in the classroom

because classrooms these days are too bright and too cluttered on the walls". She also outlined a

need for retreat in the following excerpt:

> Have a room that the kids can go to. It's not a sensory room, but a calming room, where
> they can go and do their schoolwork because it's not a sensory room. They can do their
> schoolwork somewhere where it's not as bright, not as loud, and not as hectic.

Violet, who worked as a classroom teacher herself for several years before changing

careers, also articulated her suggestions to support students with ASD in today's busy classroom

environments:

> Teachers don't have a lot of control over their rooms, so try and have as concrete and
> predictable a classroom as you can so that that child isn't constantly getting distracted and
> anxious. That can help. It doesn't completely take everything away but it helps. And if
> something is going to change, let them know in advance. Or we'll freak out. Schools
> need to have quiet places, for kids on the spectrum to retreat to.

The themes of overwhelming demands in school settings and the need for retreat is

significant because it speaks to the need to strongly consider environmental factors when

planning for students living with ASD. There may be a misconception that all students must or

should be taught within the four walls of a typical inclusive classroom setting, regardless of

personal circumstances and characteristics. However, if we consider that inclusion is not a

location but instead, a way of thinking and acting that accommodates differences and does not

view them as deficits, we need to rethink how we choose to use our places and spaces within

schools to provide the optimal learning environment for students with diverse needs and abilities.

Theme 3: Anxious and scared

Feelings of anxiety and fear characterized the stories of the lived experiences of the

majority of participants as they described their school years. Given the idea that sensitivity to

sensory input is a characteristic of students with ASD, it is not difficult to imagine how the

demands of a busy school environment might lead to a perpetual state of worry and fright. This

state was described in various ways, including "anxious", "so very scared", "panicked", "very

suicidal for a while', "depressed from always being worried:, "scared", "afraid" and "a chronic

state of anxiety" which caused one individual to express that she "would burst into tears"

regularly at school.

 Kelly-Ann, who self-diagnosed her ASD once her own two children exhibited similar

behaviours and were diagnosed themselves, picked almost constantly at her cuticles as she

struggled to explain how profoundly affected by anxiety her school years were:

> There was anxiety around just not knowing how to calm my physical nerves from…and
>
> not knowing back then that it was because of my clothes, that it was because of the way
>
> other kids would touch me, or wanting to tell people that I didn't like their voice, or going
>
> to school and not knowing if… I mean, if I'd be allowed to leave the classroom because
>
> it's too loud. So there was a lot of… well, I look back and there was so much anxiety, the
>
> anxiety of not knowing back then how to deal with my having Asperger's as well as not
>
> having anyone around me know how to figure it out.

Two main sub-themes related to anxiety and fear emerged from the data were anxiety and fear stemming from unpredictability at school, and seeking and needing control as a way to cope.

Unpredictability.

Fear and anxiety related to the unpredictability of social interactions with teachers and peers, was a commonly voiced experience, as were unpredictable school-related events and transitions between educational settings. Kelly-Ann verbalized that the worst situations she faced in school were during times that she needed to "fly by the seat of her pants". Bailey described her fear about leaving the predictability of her high school to enter a post-secondary institution and that her last year in high school was marked by "severe anxiety" for this reason.

Situations that might not be overly anxiety-provoking for typically developing children, such as accidently being bumped by a peer in the hallway or inadvertently making an error in schoolwork were cause for heightened emotional responses in participants. Bailey spoke of the mutual feelings of fear between her and one of her elementary school teachers and her memory of her own extreme reaction to making a spelling mistake:

> My grade three teacher was genuinely afraid of me. She told my mother that she was afraid of me and didn't understand why I would react to things the way I reacted to things. If the teacher would say something like, "Oh, you spelled that word wrong", most kids would think, "Oh, I spelled that word wrong", but for me… I would burst into tears. She didn't know what was happening. So she was terrified… but I was terrified too!

Social events which students typically look forward to during high school were described as full of potentially unpredictable and anxiety-provoking situations. Kelly-Ann articulated this as characteristic of her teenage years:

There was anxiety going to parties, because I was being expected to go to parties. "Your sister goes to parties. Why don't you? It's the only way you'll make friends." I never knew what to expect at parties! The non-awareness… not enough awareness of what it meant to have Asperger's back then. Nobody knew how really hard it was to go to parties and things.

Listening to the various strategies individuals used to cope with heightened levels of anxiety and fear due to unpredictable people and experiences at or related to school events provided me with much insight. It seemed that the unpredictability of social interactions and experiences could be overwhelming and that retreating or reverting to more predictable topics of conversation and subject matter could help to overcome this feeling. Some participants described the experience of immersing themselves in activities and topics that were familiar and comforting. For example, Marli expressed that "there are people on the spectrum who love Pokémon and are really into that" and Violet described her "obsession with Doctor Who". I wondered if knowing a lot about a particular book series, movie, TV show or any other topic brought about a sense of peace of mind in an otherwise often chaotic world.

Within school subject matter, mathematics appeared to provide a sense of predictability that was not as evident in other curriculum areas. Bailey described math as easy for her:

I have the time to think through it before I have to do it. Math stuff is formulaic. You do the same thing every time and go through the steps. You know what's going to happen.

This tendency to gravitate towards familiar subject matter seemed to lessen feelings of fear and anxiety, and provided a sense of safety and predictability. This was especially evident during social interactions because, as Violet expressed, "we know that we are supposed to be

having a conversation with you but we don't know what else to say, so we talk about what we know". However, this often led to increased social isolation as peers failed to understand it:

> We'll prattle on for hours about what we're obsessed with because we're supposed to be talking with you. Not, "Hi, how are you?" but more, "Oh, did you know that the F120 runs at 150 miles per hour?" Trains! Okay, I made that fact up, but you see what I mean? And to your peers, what you're obsessed with can seem really childish. And it is often childish, because it's simple. Something we can get lost in, because our minds are always so busy and can go to some dark places. It's something familiar and something you know. You can know everything about it and to have that expertise, it helps with your anxiety. It's not going to hurt you. I think where the anxiety comes from is just the constant unease of not knowing what we're supposed to be doing or saying. The constant of not knowing anything. Something to control when you can't control anything else.

It's important to note that the anxiety and fear that characterized interactions and other unpredictable situations arising at school pervaded participants' stories at every level, whether it be elementary, middle or high school years. It was not as if they were limited to a particular period of time during their educational careers. It was evident that these were chronic feelings and states which typified most if not all school days.

Seeking and needing control.

Seeking and needing control while anxious and fearful emerged as a characteristic common to participants. Bailey expressed her desperate attempt to take measures to ensure she was sitting with a familiar peer in her Kindergarten class:

I would always try to be in her group for everything. I'd rearrange the place mats so that

hers was next to mine. I would end up sitting next to her for snack and stuff like that. I

didn't understand why at the time. I would do it when the teacher wasn't looking.

It was important to Violet that I understand the difference between looking for control to

gain a sense of power, as opposed to the idea of *needing* it in order to overcome her anxiety. She

insisted that many individuals living with ASD not only seek but need a sense of control, and

that schools need to acknowledge and provide for this:

> I think that's probably common for people on the spectrum… feeling out of control. We
>
> need to feel we have control of something. Our brains basically behave like we've got
>
> PTSD. Some of that earlier experience is traumatic. And people, in schools and
>
> otherwise, are not taking it seriously. That's the worst.

Some participants expressed that learning more about their anxiety and fear as adults

provided some understanding that they did not have earlier in their lives. Violet stated this

realization with accompanying hand gestures indicating general areas of the brain:

> My therapist explained to me what happens when you go to "that place". The left side of
>
> your brain completely shuts down. There's no logic, no language, nothing. And so what
>
> can that child do but scream? He said that when you are in a constant state of anxiety, the
>
> left side of your brain does not function the way it's supposed to. And yet somehow
>
> people who are on the autism spectrum can still manage to be logical and learn and have
>
> language skills. And so in talking to him, I realized how much I'm actually capable of,
>
> you know? The anxiety that I have would put most people in bed and they wouldn't be

able to do anything. And I get up in that state of anxiety every day and I function. And so

that helped me understand.

Given the social and physical demands of a school environment, it is crucial that there is

an understanding of the role that fear and anxiety play in the way students with autism behave

and react in everyday situations. Each school day brings countless moments of unpredictability –

whether it is an unfamiliar substitute teacher, a change in the schedule due to a school assembly,

a sharply raised voice of a teacher reprimanding a classmate, or an unexpected confrontation

with a school staff member having a bad day. To assume that students with ASD may be

consciously and deliberately reacting in extreme ways prevents schools from responding

appropriately and supportively to behaviours likely rooted in anxiety and fear.

In addition, providing opportunities for students to have their thoughts and ideas heard

and find control in a setting often controlled almost exclusively by adults seems paramount. It is

incumbent upon school staff to recognize that a desire for control by students with ASD is often

in response to overwhelming anxiety over unpredictable situations at school rather than a blatant

disregard for authority or deliberate defiance.

Theme 4: Need for support

All participants in the research stressed the importance of schools taking an active role in

supporting the particular needs of students living with ASD. Many spoke of the need for the

dissemination of research to teachers, towards the goal of improving the learning conditions of

current students as well as those children with ASD entering schools in the future. From the

voices of the participants, two sub-themes emerged as being essential to a positive school

experience. In addition to supporting overall academic and social development, they were

perceived as helpful in overcoming challenges associated with the characteristics of autism, such as hypersensitivity to sensory stimuli and feelings of anxiety.

The two sub-themes that emerged within this theme were understanding and compassion, and the supportive effects of using a strengths-based approach to working with students with ASD.

Understanding and compassion.

Participant voices were unanimous in their wish to emphasize the need for all involved in supporting children with ASD in schools to employ understanding and compassion. They especially appreciated knowledgeable teachers who were flexible, who allowed them to be understood and heard, and who made accommodations for their unique needs. Marli articulated that relatively simple measures such as "modifying questions" and providing both oral and written instructions were helpful to her. In a rare moment of enthusiasm during his interview, Pokémon spoke in an animated voice about an enjoyable assignment in which he had been given choice in how to demonstrate his learning:

To Kill a Mockingbird… I had a really fun project from that book. It was one of the projects we did in our English class. I can't remember if it was Grade 10 or 11. I took one of the scenes from the book and I made a ham. One of the main characters had to dress up as a ham. I made the character. She's the daughter of the main character and in the book, she dresses up as a ham. I had to make it out of papier maché. We still have that ham!

In addition to offering flexibility in school assignment requirements, Carrie emphasized the role that recent advances in technology can play in supporting students with ASD and related

needs. She recommended that educators become knowledgeable about the variety of software available to students:

> The biggest useful thing I've had is adaptive software. It puts the control in my hands. The biggest one is text-to-speech for me, but I've noticed that I also have a lot of trouble putting things in sequence, like 'this comes after that'. It needs to be adapted. So I have software that has pictures and you can put them in sequences or have a flow chart.

However Kelly-Ann was quick to point out that a teaching approach or strategy that works for one student with ASD might not necessarily work for another:

> I'd like teachers to realize that they sometimes just need to tweak their teaching styles, and to realize that these kids are individuals who need a little bit more help than your typical kids in school. Also that each one is different, and so how you teach one kid is not necessarily what the other kid needs… not to lump all the ASD kids into one.

Possessing knowledge about ASD, or seeking to understand its characteristics without focusing on its origin was important to Violet, and she advised educators to remember the following:

> It's more important to know how to deal with it. Why are so many concerned about where it comes from? Some people still think it can be cured. No, you can't catch the autism. It's like people used to say that people were faking being homosexual. You can't catch that and you can't catch things like autism. They just are. You don't choose your gender orientation or the person you are. You just are that person.

Bailey advised teachers to "trust their students to know what they need" and shared a story of a teacher who recognized that she was struggling with friendships:

She came up to me the first day in class. I think she may or may not have arranged the

class specifically so that I could be in a class with the one person I knew in the whole

school. She really was the first teacher to understand me.

In listening to the stories of successful experiences in schools, it became apparent that the student-teacher relationship was a crucial contributing factor. Educators who took the time to gain a deep understanding of what strategies and approaches did and did not support their students with ASD were instrumental in providing a supportive, attuned and rich school experience for these students.

Using a strengths-based approach.

Descriptions of school experiences that supported the social and academic needs of participants consistently contained the idea that focusing on their interests, passions and what they were able to do well was essential. When their differences were perceived as problematic by educators, descriptions of their experiences were remembered as poor and as hindering their success at school.

Marli, finishing up courses at high school, expressed that she had many interests, that she was a hard worker and that she could do "complex things". She was looking forward to learning the skills required to become a merchandiser, and she enjoyed any opportunity to draw and paint:

I have good memories of art. I paint with watercolours. I started art as a child, using oil

pastels. My teachers helped me. My school makes me happy. I took Miss A's art class

last school year and painted a landscape mural.

Pokémon contrasted the experiences he had with two teachers in elementary school, one

who taught him as if he were just another member of the classroom and one who taught him like

he shouldn't be in the classroom because he "was different". Teachers' reactions to differences varied widely in participants' stories – some participants stated that they were cause for exclusion from regular classroom activities while others did not. Violet thought it was important for teachers to allow students with ASD to share knowledge in areas in which they were passionate:

> If we know more about a subject than you, don't be offended and don't assert your position. If you have a kid in Grade 6 who knows more than you do about what you're teaching, utilize that child. Have them help you create lessons, or have them teach a lesson once a month. A lot of teachers get defensive when the students know more. Get those kids to help. Get them involved.

Several participants were old enough to have witnessed positive changes in societal views towards children with ASD. While Kelly-Ann recounted mostly negative memories of her own schooling, she felt that her children's experiences were improved:

> Being a child with Asperger's back then was not a very good thing. I can see it now, with my son. I see all the awareness that's out there. It's actually… it's turning into a more positive thing. People are looking at kids with Asperger's now in a more positive light. My son's got almost a picture memory. He loves cars and he watches these crash test videos on TV where they crash the vehicles and then they take the rating. All he has to do is watch the videos once or twice and he'll be able to walk down the street and tell you the make and model of every car, and the crash test rating.

Bailey reiterated the importance of educators adopting a strengths-based approach and using creativity when designing tasks and activities for students with ASD. She advised that

teachers accept them and get to know them the same way they would get to know neurotypical students:

> Approach us from where we're at. If the kid likes beluga whales… approach him by adding up fish to feed the beluga whales. Making whatever fit our way of thinking rather than making the kid fit whatever your idea is.

Carrie's teachers for a substantial part of her school career were her university-educated parents, and her experience differed markedly from other participants. She was quick to note that their attitude towards her ASD was based upon an attitude that she was "amazing":

> They didn't see my differences as pathology. Or talk about them that way, which I think is really important. My parents are really supportive and my dad is an over-the-top cheerleader. Just to have someone who is very enthusiastic about what I did was really neat. It would be good if teachers would see the strengths in kids and that they talk to the kids in terms of strengths. If they saw the differences and separated the kids from the differences. Seeing what they are able to do and genuinely thinking the kids are amazing!

With plans to pursue her medical degree with a specialization in neurology and a sub-specialty in developmental disorders, Carrie remarked that she hopes one day to work with families and the schools that their children attend. Her goal is "to see a world where adults and children with developmental disorders are respected, valued and empowered".

In listening to and reflecting upon the characteristics of conditions supportive in the social and academic development of students in contrast to conditions which hindered such development, it was clearly evident that identifying and building upon individual strengths, and moving away from pathology and deficit-based thinking was paramount.

Living as a Student with ASD: An Intense Reality

According to accounts of school experiences expressed by research participants in the

current study, the experience of an individual with ASD in a school setting may be summarized

as an "intensely lived reality". Participants vividly described the challenge of finding themselves

in a setting of overwhelming sensory input filled with ongoing demands that they were ill-

equipped to cope with given the characteristics of their condition. To complicate an already

difficult scenario, they felt alone, strange and different from peers, and could rarely find solace

unless they were fortunate enough to "land" in a school where support took the form of

compassionate teachers, a positive peer group and somewhere in the school building to retreat to

when needed. The following narrative was created by incorporating the varied descriptions of

the school experiences of participants into a composite scenario. If we could experience the

thought process and sensory experience of a student with ASD in a typical elementary school

classroom setting, perhaps it would be something like this:

> *The squeaking of the chairs on the blue and white tile floors assaults my ears, and the*
>
> *commotion of twenty-something bodies crammed into the confined area of a coat room*
>
> *feels like I'm being suffocated. The newly designed bulletin board, carefully prepared by*
>
> *my teacher to display student artwork inspired by Picasso, is almost painful in colour and*
>
> *sheen. The stale odour of gym clothes that should have been laundered weeks ago is*
>
> *intense. There is a substitute teacher today and he hasn't changed the visual schedule on*
>
> *the board to show when we have gym class. My body is unsettled and I can't keep it in on*
>
> *this chair. Can I go in the hallway for some air? The teacher starts speaking and I feel*
>
> *his eyes penetrating my space. He looks scary, with thick, dark eyebrows that are close*

together. Will he hurt me? He's speaking to Mrs. T who is moving to sit beside me. Thank goodness she's here today. She knows that the schedule should change and walks over to the board to correct it. The morning announcements blare over the PA system. I need to move to another chair and get up to switch. Everyone turns to look at me. They stare holes in me and then look away. They don't sit on chairs like me; they're sitting on the carpet and don't seem to notice that it's 9:17 and we didn't chart the temperature like we always do. My body needs to move. The kid closest to my chair moves away when my leg kicks. Is it recess yet? It's windy today and I might get blown right off the field. The two girls who always call each other names when my teacher Ms. W is not here should not be sitting together. Their voices are getting louder and louder. I want to crawl into my bed at home. The substitute teacher holds out a paper with some math questions on it. It's like the one we did yesterday so I know what to do. I look at the clock. "Thirteen minutes until library. Should we go do your math there?" asks Mrs. T. She coughs. I hope she isn't sick, and I hope Ms. W is coming back tomorrow.

This narrative is intended to paint a picture of what a student with ASD might experience at school, and may be useful in prompting educators to reflect upon what changes to policy and practice might better serve this child's strengths, needs and interests, as well as those of classmates.

Chapter Five

Discussion

The intent of my research study was to contribute to the body of work dedicated to honouring the voices of individuals with ASD and using them to inform our understandings of how to improve inclusive school environments. I examined educational practice by soliciting the perspective of students on the ASD spectrum. In doing so, my study focused on identifying practices and conditions that either supported or undermined the social and academic progress of students with ASD, as well as what educators could learn from the school experiences of these students. With increased knowledge of how to best support students with ASD gained as a result of this information, we as educators are in a better position to provide current and future students with an enriching and engaging school experience. As a researcher, I aimed to design my study in a way that would empower, value and privilege the voices of people with ASD, who have for too long had others speaking on their behalf. Listening and learning from participants' firsthand experiences and using their 'unfiltered' stories as a direct and sole source of data were essential components of my study.

My study resulted in several key findings. The school experiences of the participants were characterized by social isolation, lack of friends and bullying. The school environment presented the challenge of sensory overload, requiring a space for, and time to retreat in order to cope with the demands. Participants reported feeling anxious and fearful a lot of the time, partially due to the unpredictability of social interactions and typical school activities. Seeking control amidst the busy school setting was a commonly expressed need. Support in the form of understanding and compassion from peers and teachers was remembered with gratitude, as well as efforts to view and support students with ASD from a strengths-based perspective. These

findings have far-reaching implications for educators and for stakeholders involved in improving educational outcomes for students.

Implications

The results of the study point to several implications for schools in their efforts to better support students with ASD. Five areas of learning that link to the key findings and which are discussed at greater length are as follows:

- educating colleagues and stakeholders

- rethinking school spaces

- planning with purpose

- changing mindsets

- nurturing strengths and interests

Educating colleagues and stakeholders.

The results of my study imply a need for educators at all stages in their careers to gain a greater understanding about what it means to have ASD, what students with ASD face in their daily lives at school and what they can do to support their learning. One teacher's interpretation of what autism is and how a student experiences a school day may be radically different from another's, depending on a variety of factors including personal beliefs, values, attitudes and experiences, information gained via sources in the media and opportunities for professional development that they may have been accessed. It may be valuable to provide pre-service teachers with education in this area prior to the start of their teaching careers so that they are better equipped to offer support to students with ASD in their future classrooms. Current educators may benefit from learning about more contemporary perspectives and understandings

given that knowledge about ASD has increased dramatically in recent years and continues to develop. Committed school leaders are in a position to set the tone and contribute to a school culture which values learning about differences as aspects to be honoured, and how to respond to student needs from a strengths-based perspective. The responsibility to include the voices of students with ASD in planning for their school experiences should be acknowledged, respected and acted upon. Decisions should include student perspective as much as possible, and self-advocacy opportunities should be encouraged and supported.

For instance, knowing that students with ASD often experience social isolation may encourage teachers to spearhead initiatives designed to foster social-emotional development and connections between peers, especially if the student expresses that he or she is negatively impacted by feeling different and secluded. These efforts may take many forms and will likely depend largely upon what is supportive to individual students. Checking in frequently with students and asking for their perspective and feedback may reduce the chances that their school experiences are lonely ones. Helping the student with ASD access a few trusted adults in the school environment to speak with when needing assistance could help reduce anxiety, incidents of bullying and bring about awareness among colleagues and peers. Including the voices of students with ASD in discussions around initiatives intended to support them in schools is crucial.

Schools are privileged to influence the education of not only students but also the wider community. Inviting other stakeholders – such as parents, school trustees, early childhood care personnel, peers and community members – to be part of conversations about ASD broadens the audience having access to current information, and has the potential to positively impact upon how students with ASD are viewed and heard.

Rethinking school spaces.

Addressing the needs of students with ASD within an inclusive school setting can prove challenging, especially if notions of inclusion are not fully understood. Inclusion is "a way of thinking and acting that allows every individual to feel accepted, valued, and safe" (Manitoba Education and Training, 2017) which implies differences in individual strengths and needs. There is still an idea amongst some educators that inclusion is a location, and that educating diverse learners means that all students, regardless of unique circumstances and needs should remain in the classroom setting at all times. This view does not serve students with ASD well, because the results of the study reveal that the demands of the classroom setting are often overwhelming, bombarding them with sensory information and causing undue anxiety. Exploring alternatives to classroom-based learning, or consciously designing classrooms with sensory needs in mind may meet the needs of individual students and maximize their educational experiences. A typical school building's physical structure, facilities and layout may be much less inclusive – that is, much less safe for autistic students with highly sensitive neurological systems - than we think it is. Assessing environmental characteristics is crucial in ruling out factors that may be impeding student achievement.

The appeal by research participants for places and spaces within schools for the purposes of retreat during the day should be heard and respected. However, the complexity of ASD and the fact that individual differences between students exist imply careful consideration of what elements are needed to meet the need for retreat. One student may benefit from regularly scheduled movement breaks spread throughout the school day, while another might benefit from spending the last hour of the school day working alongside a peer in a quiet room with dim lighting. At all times, student voices need to be included in these conversations. The balance of

time spent in the regular classroom versus alternative spaces needs to be negotiated and to take into consideration individual circumstances and needs.

Planning with purpose.

Planning for the needs of students with ASD requires careful thought and attention. My study underlined the significance of high sensory input and unpredictability as two of the many challenging aspects of a school environment that can often lead to students feeling anxious, fearful and desperate to regain a sense of control. Informed planning for students necessitates knowing them deeply, and purposefully providing what is required to optimize the learning environment. It may involve a team of advocates to determine what next steps are needed in the planning process, and at all times it requires dedicated team members who are invested in the student's education and who value the inherent value and potential of students regardless of unexpected behaviours they may exhibit. Again, including students' voices in conversations around planning is vital. This might entail having students actively involved during student-led conferences during reporting periods throughout the year, or inviting them to participate in meetings during which IEPs (Individualized Education Plans) are created and revised on a regular basis.

Due to the fact that planning is such a unique endeavour for individual students with ASD, it may look completely different for one student than for another. If bullying is a problem, providing peer escorts or additional adult supervision may be effective. If unpredictability is a concern, tools such as visual schedules, visual timers, transitional objects and a particularly flexible, creative teacher may help to support the student. Students with ASD may find adaptive software to be key in unlocking their potential to access learning that is inaccessible otherwise. The key in planning with purpose is in documenting factual information, including the student's

voice as much as possible by actively requesting their thoughts and ideas, and in reevaluating the student's school experiences on a regular basis to determine what is supporting and what may be impacting negatively on the student's social and academic progress.

Changing mindsets.

One of the most important areas of learning gained from my study was that teacher attitudes towards ASD impact heavily upon students' experiences at school. When there is a narrow or inflexible mindset around what learning should be taking place, and where, how and when it should happen, it was expressed that there was likely to be a detrimental effect on students with ASD. Educators with openness and flexibility towards evaluating and modifying factors such as classroom routines, physical arrangements, timetabling and their own expectations about students are better poised to respond to the diverse strengths and needs of students including those living with ASD. Where there were teachers who endeavoured to make learning interesting, engaging and responsive to individual needs and interests, students with ASD expressed enjoyment and appreciation. Having voice and choice in their school day was significant as a condition deemed to be supportive to students' progress in academic and social domains. These conditions helped to fulfill a need for control and lessen feelings of anxiety and fear. Educators who are open to actively listening to students about what environmental conditions they feel are important in encouraging their social and academic achievement, and who will act upon them as much as possible, are those who will make a positive difference in their lives.

The need for understanding and compassion from teachers was strongly articulated. While changing an educator's mindset on any issue might prove challenging, it seems that providing information about the importance of a supportive teacher in the lives of students with

ASD could be a worthwhile venture. This would include sharing information not only about what it means to live with ASD but also to challenge deficit-based constructions of disability that continue to prevail and which educators may still possess. Gaining knowledge about why students with ASD may not be receiving an education that maximizes their potential as well as concrete suggestions for how to support them more capably as educators may go a long way in improving the school experiences for these students.

The need to change the attitudes of peers is an additional implication arising from the research. The social isolation, lack of friends and bullying experienced by students with ASD were aspects of schooling that were very memorable and impactful for the majority of participants. In order to help improve the experiences of students who feel alone in their schools despite being surrounded by classmates and educators, there could be several changes to practice. Educating peers about ASD, not unlike efforts to educate them about other forms of diversity such as cultural differences and gender identity and expression, might result in improved understanding and compassion. Classmates who identify particular behaviours, such as someone dominating a conversation with a topic that holds little interest to them, might be less likely to react negatively and be more likely to support their possibly anxious peers with ASD if they realized that many are struggling with social demands. Buddies or mentors could be recruited to help navigate the social landscape of a school and the many complex interactions that take place within it each day. The premise of inclusion is that every student feel valued, safe and accepted. When teachers and peers actively participate in discussions and activities focused on the purpose of inclusion as well as the many forms of diversity that exist, including neurodiversity, everyone stands to gain.

Changing mindsets is a lofty goal in many respects, but efforts to enhance the educational

experiences and full inclusion of students with ASD are likely to fail without attention to the beliefs and attitudes of neurotypical individuals who make up the mainstream population in our schools.

Nurturing strengths and interests.

Adopting a strengths-based approach to working with students with ASD implies identifying and nurturing individual interests and capitalizing as much as possible on what they can do instead of what they cannot. My study revealed that tapping into students' abilities and recognizing their unique gifts – or viewing them as "amazing" as one participant proposed – was supportive and effective in furthering social and academic progress. Strategies for supporting students need not and should not take on the skill deficit-focused approach that many traditional interventions such as ABA espouse. Channeling the energy and interest of students with ASD not only has the potential to improve their academic progress but also stands to enhance social outcomes as peers recognize that differences can lay the foundation for success at school and beyond. The deeper learning that arises from exploring a topic fully and in intricate detail is something that may lead to great outcomes in future endeavours. Students with specific passions and interests might be encouraged and supported to locate others interested in forming special interest groups, social networks and clubs. Opportunities for leadership could be provided by school personnel who recognize that students possess knowledge and skills that are worth sharing with others in a workshop or conference of some type. At the same time that the teacher celebrates the unique strengths of the student with ASD, other students are influenced to view their peer and each other in this manner as well. Relationships formed between students and educators and which are founded upon gifts, talents, strengths and interests foster healthy self-esteem and the type of school environment that fosters social and academic achievement for all

involved.

Recommendations

The results of this research prompt a number of recommendations. These recommendations link with the research questions that served to guide my study, answering what educators stand to learn from the voices of students with ASD, and what conditions and practices supported their social and academic progress in schools:

Become informed.

All personnel, whether they are educational assistants, teachers, support staff, principals as well as those involved in the administration of schools as superintendents, school trustees or various other positions in school governance need to equip themselves with the knowledge and tools necessary to better understand and respond to the needs and interests of students with ASD. Seeking current and progressive information, especially from sources that privilege the voices of those individuals living with ASD, may help to counteract deficit-based and degrading notions that have dominated discourse and practice in education and other fields for so many years. Listening carefully to students and soliciting their feedback may prove helpful. For example, a new and exciting physical education program was recently offered to a class of students at the school in which I work. The students were to learn the basics of playing hockey, in partnership with players from a local team. Implementation of the program involved having students practice their skills in a large, cavernous arena with loud, pulsating music emanating from a robust sound system. Many of the students with ASD, as well as a few of their neurotypical peers with sensitivity to sound were distressed by the intensity of the music. It was only when one of the students exhibited a pattern of behaviour of purposefully delaying his entry into the arena by requesting multiple requests to use the washroom that the supervising adults realized

the impact of the music on the student's resistance to participate. Unless accurate information is embraced by all involved in planning educational opportunities for students with ASD, the risk of maintaining ineffective practice remains.

Explore perceptions and evaluate current educational policies and practices.

It is important to acknowledge that we continue to privilege fields such as psychology and special education approaches, whereas efforts to view students with ASD through the lens of critical disability allow for new, enabling narratives of autism (and other disabilities) to emerge. Current common practices in schools include the identification of a student with special needs such as those associated with ASD, an intake meeting during which caregivers and school personnel discuss the needs of the student in question (often without the student's presence and participation) and a lengthy, formidable and often deficit-driven application process to obtain funding from the provincial government to help support costs associated inclusion of the student in the classroom. These systemic policies and practices may not serve the best interests of students and may well maintain deficit-focused approaches. Reflecting upon and questioning traditional procedures and processes may allow for the development of creative, strengths-based practices. For example, the content of a student's IEP often includes comments about a student's current performance and proceeds with detailed goals related to skill deficits in various areas of learning. One child with ASD with whom I worked had an IEP containing a goal to colour within the lines of a one-inch square by the end of his Kindergarten year. As part of a school team, I contributed to a discussion with the ABA consultant who proposed the goal concerning why this objective was not only inappropriate, irrelevant and meaningless for the child in question, but also for any child in the Kindergarten class.

Simply changing the format of the IEP to begin with a list of student strengths and abilities sets the tone for a more enabling, positively framed document. Using the language of "passions and interests" rather than "obsessions and perseverations" is a progressive step towards seeing students first as individuals with gifts and talents to share rather than deficiencies to fix. Changing the language, labels and categories we use to describe difference is essential if we are to construct and advance enabling and empowering interpretations.

Support student self-advocacy and voice.

Initiatives designed to encourage, facilitate and support the self-advocacy and inclusion of voices of students with ASD in conversations and decision-making are crucial. Schools are places where we hope all students will develop the skills to become critical thinkers and active citizens. However, the development of such skills benefits from practice and the assistance of educators. Facilitating the participation of students with ASD in student-led conferences and their own IEP meetings as previously mentioned are positive steps towards this goal. Initiatives that encourage the sharing of autistic perspective may help to provide opportunities to learn strategies to practice aspects of public speaking and/or persuasive writing. Promoting self-advocacy groups and their causes as much as possible may support students in forming friendships, social networks and opportunities to share their experiences, thoughts and ideas with the larger community, including bodies that influence policy and practice. Students who have developed skills in self-advocacy may be more likely to continue such efforts well into adulthood and contribute to the political arena.

On a more local level, schools might utilize professional development days to invite a members of the autistic community to share their experiences as students with educators, and may also serve as mentors to students with ASD. For instance, a student pursuing a university

degree in fine arts was invited as a guest presenter to one of the classrooms in a school in which I

worked. Not only was he able to work with younger students and share his artistic talents with

them; he was living proof that someone who struggled to "fit in" during his youth was achieving

success in an area in which he is passionate while also acting as a role model for others. In

another case, a young student with extraordinary talent in creating plasticine sculptures of

dinosaurs and sea creatures was asked to act by his classroom teacher to teach his peers some of

the techniques he used to create life-like teeth and limbs. The child eagerly accepted the

opportunity to share his expertise with classmates and the boost to his self-esteem was apparent

to all involved. Thomas and Loxley (2007) describe inclusive schools serving as powerful

examples as part of a "virtuous circle" in which "students see with their own eyes children of all

kinds and from all backgrounds valued" (p. 123). Supporting these opportunities may have

ripple effects which extend far beyond the classroom and eventually effect change in meaningful

and ground-breaking ways.

Advocate for strengths-based policy and practice in the larger community.

In an era where politicians and policy makers seem much more concerned with

"improving standards" through measures such as standardized testing, comparison of students

and analyzing quantitative data than with providing the support needed to promote equitable

learning environments in which all students can thrive, it is incumbent upon educators,

researchers and academics to engage with local, provincial and national governments. Educators

may feel as if they hold no power in arenas such as these, however continued pressure and

advocacy may ultimately succeed in convincing those in positions of power and influence to do

away with archaic views about students with exceptionalities and embrace contemporary models

of learning based upon communities of learners who believe in the inherent value of all of its

members regardless of ability. For example, speaking against the continued use of provincially

mandated performance assessments - which are based upon comparing, sorting, categorizing and

ultimately valuing some students over others - may result in pressure to take a closer look at

policies and procedures governing education. Other systems such as healthcare need to examine

the process by which children with ASD are diagnosed, as there continues to be a "doom and

gloom" portrayal conveyed to families which is highly difficult to alter once presented.   The

voice of the child, of course, is lost.

    Advancing enabling, strengths-based language, policy and practice has the potential to

bring about interpretations that challenge social, cultural, political and relational barriers that

individuals with ASD continue to face. Central in this effort is prioritizing and celebrating the

voices of the people who live the experience, as experts in understanding their own lives and as

primary agents of change.

Limitations

    Personal bias.

Personal bias related to this research has impacted upon this study from the onset. My

perspective towards supporting students with ASD has been based upon theoretical learnings and

the belief that any differences they may have from the neurotypical population do not equate to

"less than". As many other theorists and authors have suggested, neurotypical individuals have

much to learn from people with ASD. After many years of working in schools in a role created

to help teachers provide an enriching and positive experience for diverse learners of many

abilities, I had already concluded that the responsibility lies within teachers to change their

practice and within schools to change their systemic processes and procedures to accommodate

students' needs and interests. This is in stark contrast to the idea that students with ASD need to

change to fit our current school systems, environments and practices.

My study originated out of a desire to learn directly from individuals with ASD and to advance the theoretical underpinnings of the work. Listening to their stories caused me to reflect upon my experiences as a teacher and as someone who continues to argue in favour of strengths-based approaches which believe in the inherent value and worth of all students who enter our schools. The focus of my research was on gathering information from participants by asking open-ended questions and keeping my own input to the conversations as minimal as possible. At no time was I involved in encouraging any particular response, position or attitude. I was clear in conveying to participants that they were participating in a study, explaining the purposes of the study, and ensuring that there was no deception about the nature of the study. After the interviews took place, a careful analysis of the thoughts and ideas of all participants was conducted. My study was intentionally designed in a way to challenge predominantly deficit-based professional discourse, and interpretations of the data are affected by the assumptions I brought to the topic.

Small sample size.

This study was designed to explore the school experiences of adults with ASD in a way that would encourage deep and rich story-telling. The stories came from six adults from a single city in a relatively small urban city in Canada. Having a larger sample size would have broadened the number of experiences and stories told in this study. This could very well have had an effect on the results.

Primarily female participants.

I was surprised that the responses to my recruitment efforts for this research were from predominantly female participants, especially given the current statistics that ASD is diagnosed

far more often in males than females. There was only one male participant in the study. While

the contributions from all participants were valuable and rich in information and implications, I

wonder if having more stories and experiences from male voices may have impacted upon any of

the themes that emerged. Males and females may process sensory information and the world

around them differently. Incorporating more male voice into the study may have brought

forward more themes and experiences, thereby expanding the body of information from which to

learn. It was unfortunate that more male voices were not able to be included in the stories.

Future Research

On the basis of previous research and this study, it is clear that there is a distinct lack of

autism research embracing a qualitative, critical disability paradigm (Glynne-Owen, 2010), and

that listening to the voices of students with ASD can provide valuable information that can

impact school practice (Saggers, Hwang & Mercer, 2011). There is a great need for further

attention towards supporting students with ASD in our schools, and for further research in this

area. While it was relatively easy to locate research in the field of autism, very little was

conducted with individuals with ASD serving as a direct source of data. There is much work to

be done in order to move forward with research that acknowledges the significant role that the

voices of students may play in our understanding of how to improve educational practice.

Specific suggestions for future research include listening not only to adults but also to the

voices of children and adolescents with ASD as direct sources of information. In addition,

exploration of particular areas of school experience such as social isolation, which was perceived

as negative in some stories and positive in others, could be a potential research topic. Studying

teacher preparation for working with students with ASD and effective professional development

opportunities with autistic voices as the source of information could also be researched. There

might also be research conducted to examine how to facilitate sustained changes in language and practice for other vulnerable populations who struggle to have their voices heard.

A Critical Encounter – Revisited

The spark which ignited my interest and passion in learning about the educational experiences of individuals with ASD was a critical encounter with a student named Brett (a pseudonym), described in the opening to this thesis. The need to gain the ability to decipher and respond appropriately to the communicative attempts Brett's erratic behaviours were trying so desperately to convey to me during the incident on that hot summer afternoon inspired my research. My quest to learn from a student who could not speak except through non-verbal behaviour has resulted in work that continues to inspire me in many ways.

The knowledge I have gained through exploring literature and autobiographical accounts of people with ASD, combined with learning from listening to the school experiences of adult participants in my study allows me to make an informed guess about what Brett may have been trying to tell me that day. I believe now that he may have been desperate to let me know how terribly hot he was under the intense June sun, or how unbearably bright it was outside. He may have been trying to make me aware that his keen senses were so overwhelmed that it was causing his extreme distress. He might have been scared and anxious about being with me, an unfamiliar teacher who had the best of intentions but who had no idea of what he was experiencing. Brett may have been silently counting every second until he could re-enter the school and find some relief from the sun, heat, noise and movement of bodies around the schoolyard. When this relief came, I think perhaps he made every effort to calm his body. He needed support, compassion and someone who knew him much better than I did.

It would be tempting to feel a weight of guilt for what happened that day in June 2009. However, I realize that I was doing the best that I could with the knowledge and skills that I had at the time, and now that I know better, I will be able to do so much better in the future. I am also in an envious position to be able share my learning with audiences of teachers and school leaders so that they may learn from the school experiences of students with ASD as well.

My hope is that my research has played a role in an ongoing effort to bring agency, privilege and power to the voices of people with ASD, that my work resonates with advocates, activists, caregivers, autistic individuals themselves as well all stakeholders involved in educating students with ASD, and that it helps to inspire further research and work designed to include, honour and celebrate the voices of autistic people.

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APPENDIX A

[On letterhead]

Consent Form – Senior Administrator

Title of Study: An Examination of the School Experiences of Adults with Autism Spectrum Disorder
Student Researcher: Karen Hiscott

> **This consent form, a copy which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what participation will involve. If you would like more detail about something mentioned here, or not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.**

My name is Karen Hiscott and I am a Master's of Education student at the University of Manitoba, in the Department of Educational Administration, Foundations and Psychology studying in the area of Inclusive Special Education. This letter is a request to post recruitment information about a study I am conducting. My supervisor for this work is Dr. Charlotte Enns, Professor in the Faculty of Education (xxxxxxxxxx@xxxxxxx.xx); her phone number is xxx-xxx-xxxx. I would like to provide you with more information about this study and request your assistance in posting the information where potential participants may see it.

Purpose: The purpose of this study is to examine how adults identified as having ASD describe their social and academic experiences in schools. I will ask participants to reflect on how schools have supported or not supported them as students with ASD. The information will be used: (1) to analyze what aspects of school succeed or fail to support the learning and development of these individuals, according to their accounts; (2) to collect and synthesize scholarly research on the school experiences of adults with ASD; (3) to report findings to scholarly, professional and community audiences through conferences and journal articles; (4) complete a thesis on this topic.

Participation: Participation in this study is voluntary. The commitment for each participant will involve an interview of approximately one hour in length to take place in a mutually agreed upon location and time. The participants may decline to answer any of the interview questions if they wish. They may also choose to have a parent or advocate present. Furthermore, they may decide to withdraw from the study at any time and without penalty. With their permission, the interview

will be audio-recorded to facilitate the collection of accurate information, and later transcribed for analysis by me as the researcher. All information participants provide is considered confidential. Their names or any other personal identifying information will not appear in any part of the study or in any documents generated from the study. Participants will be assigned pseudonyms in order to protect their privacy. Transcriptions and/or tapes collected during this study will be retained until it is completed, and will be in a locked filing cabinet at my house and then shredded, erased or deleted. Only my advisor and I will have access to the data. Once transcribed, I intend to send participants a copy of their transcribed interviews so that they can check the accuracy of my representation of what they said. This may require up to two hours of their time.

Risk and benefits: There is minimal risk to them as participants in this study. I recognize that some may experience discomfort or anxiety when reflecting upon memories of painful school experiences, and will be sensitive to this possibility. I will stop any interview if necessary. Participants may benefit from reading the final results of the study which I will make available to them by email upon request. There will be no compensation for their participation.

If you have any questions regarding this project, or would like any additional information to assist you in reaching a decision about whether or not to post the information, please contact me by email at xxxxxxxx@xxxxxxxxxx.xx or at xxx-xxx-xxxx.

This research has been approved by the Education Nursing Research Ethics Board. If you have any questions, concerns or complaints about this project, you may contact me at xxx-xxx-xxxx or by email at mailto:xxxxxxxx@xxxxxxxxxx.xx, Dr. Enns at xxx-xxx-xxxx or mailto:xxxxxxxxxxxxxx@xxxxxxxxx.xx or the Human Ethics Secretariat at xxx-xxx-xxxx or by email at mailto:xxxxxxx@xxxxxxxxx.xx.

If you are willing to post information about this study, please read the following statement and sign and date it. One copy is yours.

I _____ agree to post information about this study. I understand that participation is voluntary and that participants may withdraw from the study at any time by simply telling the researcher. I have read and understood the above description of the study. I understand that participants' privacy will be safeguarded as explained above. I understand that if I have any questions or concerns, I may contact the researcher and/or the Human Ethics Secretariat Board at the numbers or email addresses given above.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to post information about the study. In no way does this waive their legal rights nor release the researcher or involved

institutions from their legal and professional responsibilities. Participants are free to withdraw from the study at any time and/or refrain from answering questions they prefer to omit, without prejudice or consequence. Their continued participation should be as informed as their initial consent, so they should feel free to ask for clarification or new information throughout their participation.

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project, you may contact any of the above-named persons or the Human Ethics Secretariat. A copy of this consent form has been given to you for your records and reference.

_____

Name (please print)

_____

Signature   Date

_____

Researcher's Signature   Date

[On letterhead]

PARTICIPANTS NEEDED FOR
RESEARCH IN SCHOOL EXPERIENCES OF ADULTS WITH
AUTISM SPECTRUM DISORDERS (ASD)

I am looking for volunteers to take part in a study of how adults identified as having ASD describe their experiences in school.

As a participant in this study, you would be asked to participate in an interview with the researcher, at a mutually convenient and comfortable location. Your participation would involve 1 session of approximately 60 minutes, as well as follow-up of approximately 90 minutes at a later time to check the accuracy of the information you have provided.

In order to participate, you must be diagnosed with or self-identify as having ASD and have spent at least 3 years in a school.

In appreciation for your time, you will receive the opportunity to obtain a copy of the study results, and potentially improve the school experiences of future students with ASD.

For more information about this study, or to volunteer for this study, please contact:

Karen Hiscott
Department of Educational Administration, Foundations and Psychology
at
xxx-xxx-xxxx or
email:xxxxxxxx@xxxxxxxxxx.xx

This study has been reviewed by, and received ethics clearance
through the University of Manitoba Education Nursing Research Ethics Board.
The Human Ethics Coordinator, Maggie Bowman, may be contacted at
(xxx) xxx-xxxx or by email: xxxx@xxx.xxx

APPENDIX C

[On letterhead]

Consent Form
Study title: An Examination of the School Experiences of Adults with Autism
Spectrum Disorder
Investigator: Karen Hiscott

Who am I?
I am a student at the University of Manitoba and I am doing a study about adults with Autism
Spectrum Disorder (ASD). The study is for a thesis and my advisor for the study is Dr. Charlotte
Enns. I want to see if you would like to be in this study. This form tells you about the study. If
there is anything you do not understand, please ask me or any adult you trust and feel comfortable
with.

Why am I doing this study?
I want to learn more about your experiences in school and how people who work in schools can
teach students with ASD better.

What will happen to you?

If you want to be in the study these things will happen:

1. I will ask you to meet with me in your home or another place that you feel comfortable.
   You may bring a parent or trusted adult with you if you wish.
2. The meeting will last about one hour.
3. I will ask you questions about your experiences at school. I will ask about:

   - what you remember about being in school
   - what parts of school you enjoyed
   - what parts of school made you feel frustrated
   - what was easy about being in school
   - what was hard about being in school
   - what it was like when you started school
   - what you would like teachers to know about students with ASD
   - what helped you at school
   - what did not help you at all at school
   - what you hope for children with ASD starting school
   - what you are afraid of for children with ASD starting school

4. I will record your answers to my questions on a tape recording device during our
   meeting. I will write some notes to help me remember what you said.

5. After I have listened to what you said and written down everything, I will send you a copy so you can read it and make sure I heard everything correctly.

Should I be worried about the study?

You might feel sad or anxious when talking about things that happened to you at school, but telling might help others learn and make school better for people with ASD. I will stop asking questions if you feel sad or anxious. You don't have to answer any questions you don't want to and you can stop the interview at any time.

Will being in the study help me?

This study may not help you if you have already finished going to school. But it might find out something that will help other students like you later.

What if you have any questions or worries about the study?

You can ask questions any time, now or later. You can talk to me, your family or someone else. If you want to talk to me (Karen Hiscott), you can phone xxx-xxx-xxxx or email me at xxxxxxx@xxxxxxxxxx.xx. If you want to talk to my advisor Dr. Enns, you can phone her at xxx-xxx-xxxx or email her at xxxxxxxxx.xxxx@xxxxxxxxx.xx. You can also phone the Human Ethics Coordinator Maggie Bowman at xxx-xxx-xxxx or email her at xxxxxxxxx@xxxxxxxxx.xx.

Who will know what I did in the study?

Any information you give to me will be kept private. Your real name will not be on any study paper and no one but me will know that it was you who was in the study.

Do you have to be in the study?

You do not have to be in the study. No one will be mad at you if you don't want to do this. If you don't want to be in this study, just say so. Even if you say yes now, you can change your mind later. If you say you don't want to be in the study anymore, you can choose if you would like me to keep the information you have already given to me, or if you want me to destroy it. It's up to you. If you say that you don't want to be in the study anymore, I will destroy the information that you have given me, unless you say that I can keep it.

Who will see the information from the study?

You will be given a fake name during the study. Only I will know your real name. The answers you give me will only be seen by Dr. Enns and me. I will keep the answers and your consent form locked up separately in filing cabinets in my house and I will shred or erase the papers when the study is finished. I will speak about the study to other students and people who are interested in learning about it, but I will always use your fake name so no one will know it is you who gave me the information for the study. If anyone reads the study, your fake name will always be used in the papers.

Is it safe to be in the study?

The university might look at your answers to make sure I am doing the study safely and properly.

The people who decide if the study is safe are named ENREB. They have read about my study and they have told me it is okay to do it.

Do you have any questions?
What questions do you have?

<u>Consent</u>

I want to take part in this study. I know I can change my mind at any time.

_____   Verbal consent given   Yes ☐
Print name

_____   _____
Signature of Participant   Date

 I would like a copy of the study when it is finished:

☐ Yes   ☐ No

Please send the copy to:

_____

I confirm that I have explained the study to the participant to the extent compatible with the participant's understanding, and that the participant has agreed to be in the study.

_____   _____   _____
Printed name of   Signature   Date
person obtaining consent

APPENDIX D

Individual participant guiding interview questions

The questions below may not be asked in exactly this way, as the participants may not respond to the first question as anticipated. The open-ended nature of the questions is deliberate in this type of research. Some participants like to have open, detailed questions to respond to, while others prefer to have prompts given to them throughout, and this will be at my discretion.

PSEUDONYM: _____DATE: _____
START TIME:_____ END TIME:_____DURATION:_____

Opening Comments: I am talking with you today about your experiences at school. As you may remember, I will be taping our conversation as well as taking notes so that I may better understand the comments at a later time. Are you ready to begin?

1. Please tell me about your experiences in school. *This question is intended to be open, and to allow the participant to talk as much as he is comfortable.*

2. Please describe for me what parts of school were enjoyable. Please tell me a story about something you enjoyed. What made it enjoyable? Where did it take place? Who was there? What happened?

3. Please describe for me what parts of school were frustrating. Please tell me a story about something that frustrated you at school. What made it frustrating? Where did it take place? Who was there? What happened?

4. Please describe for me what parts of school were easy. Please tell me a story about something at school that was easy for you. What made it easy? Where did it take place? Who was there? What happened?

5. Please describe for me what parts of school were hard. Please tell me a story about something that was hard for you at school. What made it hard? Where did it take place? Who was there? What happened?

6. Can you give me some idea of what it was like when you first started school?

7. What would you like teachers to know about students with autism?

8. Please describe for me what helped you most at school? What did not help you at all?

9. Please describe for me some of the hopes and fears you have for children with autism who are entering the school system.

10. What else would you like to share about your experiences at school?