Exploring the Self-Reported Experiences of Autistic High School Students

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Exploring the Self-Reported Experiences of Autistic High School Students

by

Chandra Lebenhagen

A THESIS
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Abstract
A critical review of the literature indicates that the inclusion of autistic student voice in research and education discourse is minimal, which is problematic because this gap contributes to unethical and often ineffective educational practices and ultimately, poorer education and wellbeing outcomes for autistic students. This study investigated the self-reported school experiences of autistic high school students in Canada using a critical disability theory framework and a phenomenological informed research lens. Student perception data were collected using a mixed-method convergent parallel research design where quantitative data \((n=72)\) was collected via an online survey, and qualitative data \((n=19\) open-ended responses and \(n=10\) email interviews) was collected using an open-ended survey question and a short semi-structured email interview. Participants were recruited via snowball and convenience sampling through provincial and territory autism agencies, self-advocacy groups, parent councils, superintendents of schools, and Amazon’s Mechanical Turk. Quantitative data were analyzed using descriptive statistics, and qualitative interview data were analyzed using inductive thematic analysis. Based on self-reports, this study found that generally, autistic students’ school experiences were unexceptional. However, students reported most favourably on their school experiences when they were made to feel welcome; when they had access to personalized school spaces; when they received support from their peers; and when teachers used flexible and non-stigmatizing pedagogical practices. A unique finding of this study is that over half of autistic participants shared that they preferred to use non-speaking modes of communication to interact with their teachers and peers because typing and drawing helped improve the clarity of their messages and to minimize feelings of stress and anxiety. The implications of this study are that it provides researchers, educators, and autism allies with new information based on “actually autistic” (Craine, 2020, p. 263) experiences, and it offers researchers a methodological framework to improve the authentic participation of autistic people in research.
Preface

This dissertation is an original creation of the author, Chandra Lebenhagen. Ethics approval to conduct this study was obtained from the University of Calgary. The Ethics ID for this study is REB19-0185.
Acknowledgements

With gratitude, I would like to acknowledge the people that contributed to my learning and the completion of my doctoral degree.

First, to my supervisor, Dr. Gabriela Alonso Yanez, you always provided me feedback and direction with kindness and encouragement. Our moments of celebration made me reach farther and I always left our meetings feeling more passionate about research and improving the acceptance of autistic people.

To Dr. Anusha Kassan and Dr. Man-Wai Chu, your feedback strengthened the design of this research and encouraged me to consider different ways to enhance the inclusion of autistic voice in research.

To Dr. Sharon Friesen for your willingness to help guide this study over the finish line and for providing feedback in ways that were both instructive and inspiring.

To my autistic friend and colleague, TC Waisman. For cheering me on as a legitimate autistic ally and for reaching out to offer support and encouragement throughout various stages of my research. I am so thankful that we have become friends and for the knowledge and humour you share.

To my family and friends who were patient with me and gave me time and space to study and write.

Finally, I would also like to acknowledge and express my sincere gratefulness for the students who participated in this study. Your eagerness, vulnerability, and wisdom are inspiring, and you remind me what it is to be human.
Dedication

This dissertation is dedicated to my mom, who passed away during the data collection phase of the study. You taught me to reach high and to outsmart adversity and failure. Your passion for helping children with disabilities, and those less privileged, stands behind my life work and has weaved itself into the pages I have written.
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<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>AAC</td>
<td>Augmented and Alternative Communication</td>
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<tr>
<td>ABA</td>
<td>Applied Behaviour Analysis</td>
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<tr>
<td>ADHD</td>
<td>Attention Deficit and Hyperactivity Disorder</td>
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<td>APA</td>
<td>American Psychiatric Association</td>
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<tr>
<td>ARI</td>
<td>Autism Research Institute</td>
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<tr>
<td>ASA</td>
<td>Autism Society of America</td>
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<td>ASAN</td>
<td>Autistic Self-Advocacy Network</td>
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<td>ASD</td>
<td>Autism Spectrum Disorder</td>
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<tr>
<td>CBE</td>
<td>Calgary Board of Education</td>
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<tr>
<td>CDC</td>
<td>Centre for Disease Control</td>
</tr>
<tr>
<td>CCSD</td>
<td>Calgary Catholic School Board</td>
</tr>
<tr>
<td>CCPA</td>
<td>Canadian Centre for Policy Alternatives</td>
</tr>
<tr>
<td>DSM-5</td>
<td>Diagnostic and Statistical Manual of Mental Disorders, 5th edition</td>
</tr>
<tr>
<td>DTT</td>
<td>Discrete Trial Training</td>
</tr>
<tr>
<td>FDA</td>
<td>Food and Drug Administration</td>
</tr>
<tr>
<td>IDEA</td>
<td>The Individuals with Disabilities Education Act</td>
</tr>
<tr>
<td>ISSAC</td>
<td>International Society on Augmented and Alternative Communication</td>
</tr>
<tr>
<td>LSD</td>
<td>Lysergic Acid Diethylamide</td>
</tr>
<tr>
<td>PIP</td>
<td>Pillars of Integration Process</td>
</tr>
<tr>
<td>PRHR</td>
<td>Pragmatic Health Ethics Research Unit</td>
</tr>
<tr>
<td>PEERS</td>
<td>Program for the Education and Enrichment of Social Skills</td>
</tr>
<tr>
<td>SIB</td>
<td>Self-injurious Behaviour</td>
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<tr>
<td>TEACHH</td>
<td>Treatment and Education of Autistic and Related Communication Handicapped Children</td>
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Chapter 1: Introduction

Controlling and maintaining power over legitimate forms and representation of knowledge between disabled and non-disabled persons is common in current education systems, including day-to-day classroom practices. Destabilizing ableist practices in research and education requires professionals to continually examine their ontological and epistemological positions and how their beliefs become actioned in research. For example, by questioning the language used to describe “norms” and “averages”, and in instruments standardized on the “general population” (Tremain, 2015, p.5). Encouragingly, even those who are familiar with critical disability studies have begun to evaluate the “foundational assumptions of many disciplines and fields of inquiry, as well as the methodologies that they employ. . . and the epistemological and social positioning of the researchers and theorists invested in them” (Tremain, 2015, p.2). Similarly, educators are beginning to explore the influences of power and oppression in their teaching practice by examining colonized curricula and ableist structures that perpetuate ideas of normal and abnormal student ability.

This study explored the self-reported school experiences of autistic high school students in a Canadian context using a critical disability theory framework and a phenomenological informed research lens. Student perception data were collected using a mixed-method convergent parallel research design, where both quantitative survey data and qualitative semi-structured interview data were collected using flexible synchronous and asynchronous online methods. A novel finding of this study is that over half of survey participants indicated that they preferred to use non-speaking modes of communication and seven out of ten interviewees shared that they preferred typing or drawing to communicate to help reduce feelings of anxiety and to improve the clarity of their messages.
The selection of instruments and the design of quantitative and qualitative research methods were informed by recommendations from the *Person-Oriented Autism Research Ethics* task force (Cascio et al., 2019), which suggests the following five domains should be considered when conducting research with autistic participants. The domains are 1) Individualization, 2) Acknowledgement of Lived World, 3) Respect for Holistic Personhood, 4) Empowerment in Decision Making, and 5) Researcher-Participant Relationship. The novelty and strength of this research is that it builds knowledge based on “actually autistic” (Craine, 2020, p. 263) experiences, which are frequently overlooked, muted or ignored by non-autistic people (Kourti & MacLeod, 2019).

Additionally, this study applied several human rights principles to minimize power differentials’ negative effect between non-autistic and autistic people (Marshall & Goodall, 2015). For example, specific guidelines and reference terms from the United Nation’s Convention on Rights of the Child [CRC] (CRC, 2006) were used to inform the development of the student information booklet, consent materials, and options for synchronous and asynchronous participation in the research. The specific standards and comments considered in the design of this study are listed below:

a) Autistic students have their own views and have a right to express their views freely (Article 12).

b) Autistic students have the right to freedom of expression, including seeking, receiving, and imparting information and ideas in personally meaningful ways (Article 13); and

c) Autistic students have the ability and right to self-select the least restrictive modes of communication that authentically represent their ideas and experiences (General Comment No 9).
Improving the ethical integrity of this research by applying teachings from autistic self-advocacy groups and social justice movements, including “nothing about us, without us” (Chown et al., 2017), is another way this research sought to minimize the impacts of ableism. I am deeply grateful to my autistic colleague, who provided feedback on various aspects of the research, including recruitment, and selecting questions for the survey and email interview. Lastly, to align with autistic people’s preference for the use of identity-first language (Brown, 2018), “autistics”, “autistic individuals” and “autistic students” is used throughout this dissertation in place of Autism Spectrum Disorder (ASD) as termed in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association [APA], 2013).

Overview of the Dissertation

The organization of this dissertation includes five chapters: 1) Introduction, 2) Literature Review, 3) Methods, 4) Research Findings, and 5) Discussion, Conclusion and Recommendations. The introduction provides a summary of the prevalence of autism and identifies problems that have contributed to the adverse school experiences of many autistic students—subsequently giving rationale and significance for this study. The literature review investigates medical, parent, and first-person perspectives on theories and treatment of autistic people and the subsequent impact on autistic students’ school experiences. Additionally, the justification for using a critical disability theory framework and a phenomenological informed research lens is presented. The methodology chapter explains the benefits of using a mixed-method convergent parallel research design and identifies the procedures used to select research instruments and to complete data collection and analysis. In the research findings chapter, quantitative and qualitative data sets are presented and integrated to answer the research question. Lastly, the discussion, conclusion, and recommendations chapter examine each of the
research findings in the context of inclusion, education, and policy and provides recommendations to assist educators translate research into practice.

**Problem Statement**

The number of autism diagnoses has increased over 100% in the last ten years (Autism Speaks Canada, 2018), and current estimates suggest that one in 54, or 1.8% of school-aged children are autistic (Centre for Disease Control [CDC], 2020). Comparatively, The Public Health Agency of Canada (2018) estimates that 1 in 66, or 1.5% of Canadian school-aged children are autistic. As classroom profiles become increasingly diverse and complex, systems of education have struggled with clear definitions and practices of inclusive education. Consequently, this lack of clarity has led to less than satisfactory educational and wellbeing outcomes for autistic students (Maciver et al., 2018; Lynch & Irvine, 2009; Majoko, 2016). Most noteworthy is the fact that the perspectives of speaking, minimally speaking, and non-speaking autistic youth are considerably absent from school-based discourse on effective and ethical pedagogical practices to support their learning and social success in school (Woodfield & Ashby, 2016). Critical disability theorists Paterson and Hughes (1999) suggest that this type of exclusion is oppressive because it creates a sense of “homelessness” (p.604) for autistic students who find themselves “excluded from making a contribution to the construction of the social world” (p.604) they are immersed in. The impact of the exclusion of autistic voices in education and research is evident and possibly reflected in current research that reports many autistic students are unhappy at school (Brede et al., 2017; National Autistic Society Northern Ireland, 2012) and fare more poorly in academic outcomes compared to students without disabilities (Danker et al., 2016).
Research Question and Purpose

This study includes quantitative (QUAN) and qualitative (QUAL) student perception data using a mixed-method convergent parallel design, to answer the following research question: What are the self-reported inclusive education experiences of autistic high school students in Canada?

The purpose of this investigation was first, to learn about the self-reported school experiences of autistic students attending high schools in Canada; and second, to critically examine student-centered knowledge in the context of current inclusive education policy and practice to offer recommendations for improvement.

Rational and Significance

Although there has been an increase in broad-spectrum autism-related research, the majority represents second-hand accounts from medical, educator, and parent perspectives (Brock et al., 2013; DePape & Lindsay, 2016; Marshall et al., 2015). While second-hand accounts provide diverse and valuable perspectives, this study aims to improve researcher and educator understanding of autistic students’ school experiences based on first-hand accounts and to use this knowledge to advance ethical teaching practices to support the inclusion of autistic students.

As a result of using a critical disability theory framework and a phenomenological informed research lens, autistic students were able to share their school experiences in ways that supported their unique sensory, communication, and mind-body states (Charman et al., 2011). Supporting autistic students’ authentic participation helped to ensure that the critical discussion of inclusive pedagogies remained connected to autistic students’ knowledge and unique experiences. Thus, the significance of this research is it:
a) Acts as a stimulus for change in non-autistic knowing of autistic experience, as autistic voice and perspectives become more central in research and education discourse.

b) Acts as a stimulus for change in doing as the inclusion of speaking and non-speaking autistic voices and perspectives help to inform future inclusive practice in research and education.

c) Advances the literature on inclusive best practice and generates new research on topics related to school environments and architecture; teacher education and training on inclusive pedagogies; curricular adaptions and modifications for autistic students; assessment of learning for speaking, minimally speaking, and non-speaking autistic students; and technology supports for autistic students.

d) Offers a methodological example to researchers on how to engage participants who prefer to use non-speaking modes of communication; and

e) Holds “intrinsic benefits” (Warren, 2007, p. 26) to autistic students because they feel listened to and valued (Staniszewska et al., 2011).

Researcher Perspective and Assumptions

For twenty years, I have been personally and professionally part of the autism community. I have family relationships with speaking and non-speaking people. Professionally, I have supported autistic students, their families, their teachers from pre-school to grade 12, and currently develop inclusive frameworks for school jurisdictions and professional learning curricula for educators. Being that I was a doctoral student in Educational Research and Curriculum and Learning, I did not expect to engage in familiar learning and discourse related to autism and inclusive education. However, I was not prepared for the degree of foreignness I would feel about the content nor my feeling like an outsider within my program. Optimistically,
migrating away from familiar theories and discourse has allowed me to learn new perspectives on learning theories and how our ontological and epistemological beliefs manifest in our decisions and actions towards others. As a result, I developed an interest in exploring critical posthuman and critical disability definitions of humanness related to the treatment and educational experiences of autistic people.

As a result of moving away from my preferred and familiar topic of study, I have a deeper awareness of my ableist biases and their foundations. Consequently, my goals and strategies to reduce potential barriers are more mindful, inclusive, and action oriented. For example, my commitment to include perspectives from the autistic community on the use of deficit-based language and identity-first versus person-first language has helped me to reflect on and re-position my researcher ontological and epistemological lenses. I am also more mindful and committed to defending the creation of ethical spaces to support autistic participants to share their knowledge and experiences in non-conformist ways, including ensuring that there are appropriate and flexible accommodations to support their authentic participation in research. I ultimately see my researcher position not as an authority figure, but as a conduit to help make “visible the unseen” (Spivak, 1998, p. 285) and to create space for “ambiguity and ambivalence” (De Schauwer et al., 2015, p.10) in education and research. The following researcher beliefs underscored this study:

1. Autistic students can determine the nature of the investigation to be undertaken and weigh the benefits of their participation.
2. Autistic students can independently reflect on their experiences and communicate knowledge in personally meaningful ways.
3. Autistic students can self-select preferred modes of communication that best support their unique social, communication, and sensory profile.

4. Autistic students will choose the least restrictive space and time to participate in research; and

5. Readers unfamiliar with the codes of the autistic community may feel a tension between ableist traditions and autistic knowledge and ideas presented throughout this dissertation.

Definition of Key Terms

Ableism

Ableism is a form of discrimination that devalues persons with disabilities resulting in practices that aim to remediate or cure a person’s disability (Hehir, 2002). Ableism is reflected in social and political attitudes, structures, and systems that implicitly or explicitly limit the authentic participation of disabled people (MTOWN97, 2019). There are numerous instances of ableism in education, such as having stairs leading up to the front entrance of a school, which limits accessibility for students who use walkers and wheelchairs; or using timed tests with students with a learning disability. Interestingly, time is considered by disability theorists Paterson and Hughes (1999) as “the primary criterion of exclusion and discrimination” (p.605) of disabled people.

Disability Studies and Critical Disability Theory

Disability studies is an interdisciplinary approach used to examine the social, medical, political, cultural, and economic factors that define and stigmatize disability (Dewsbury et al., 2004). Traditionally, disability theory presents two primary philosophies of disability based on social and medical models, where social conditions create disability and medical conditions create impairment (Paterson & Hughes, 1999). However, critical disability theory challenges the
social/medical distinction to include the sociology of impairment and its connection to politics, economy, and “tyrannies of perfection” (Paterson & Hughes, 1999, p. 607).

**Speaking and Non-Speaking Communication**

Speaking and non-speaking communication are ways to convey meaning while using a variety of verbal and non-verbal modes (Lebenhagen, 2019). Using the terms speaking and non-speaking does not define a person as verbal or non-verbal; instead, the terms acknowledge that speaking communication may be unreliable due to the influences of internal and external factors (Zurcher, 2017). Following is an example of an autistic mother who uses non-speaking modes to converse with her son when her speaking communication is unreliable:

> A few times I have been annoyed at myself for stuttering and he says “Mommy! Don't ever be mad at yourself for stuttering!” or, a few times, “Mommy. Stuttering. It’s a way of life.” I don't communicate with him, so he does not feel ignored. I use alternative methods of communicating with him, just not talking. I write, point, use my extremely limited repertoire of ASL signs. I once was writing to him about what to wear to church and he wrote back “Yes, mother dearest! (2017, para.12).

Examples of ableism used to defend ideological standpoints, and secure positions of power over autistic people are presented in the following chapter, the Literature Review. These illustrations draw attention to ableist substructures present in current systems of education and everyday classroom practices. Suggestions for policymakers and educators who are interested in transforming exclusionary and oppressive educational practices are offered in Chapter 5, titled Discussion, Conclusion, and Recommendations.
Chapter 2: Literature Review

Content, Scope and Organization

This literature review aims to trace the intellectual progression of the field of autism, including historical roots, significant debates, non-autistic perspectives, and identity-first perspectives. Through a critical analysis of the literature, I explore the connection between the non-recognition and misrecognition of autistic people, gaps in current research, and the subsequent impact on the school experiences of autistic students. The literature review is organized into five main sections:

1. Historical Perspectives on Theories and Treatment of Autism
2. Parent Perspectives on Theories of Disability and Inclusion
3. Identity First Perspectives on Autism, Ability, and Inclusion
4. A Review of Inclusive Education Policy and Practice; and
5. A Review of the Inclusive Education Experiences of Autistic Students

This literature review began while completing my final summer residency, where I was required to map the thinking and feeling processes I used while I completed course readings. Over the progression of two weeks, I recorded my responses as I moved through different texts that discussed ethical reflexivity, difficult knowledge, subjectification, oppression, modes of address, and listening to Otherness. While I sensed small changes in my reactions to the readings, it was not until I was able to see the gestalt of my entries that I was able to identify sizeable changes in how I interacted with and responded to the intellectual and psychological content of the readings. Although I increasingly became frustrated with the lack of a disabled perspective, I was able to see when and where I resisted new and difficult knowledge (Kumashiro, 2002). I also realized that my feelings of frustration were not directed towards the presence of Indigenous, racial,
gender, and environmental discourse, but instead were a reaction to the absence of familiar disability discourse. While feeling challenged by and appreciative of new learning and my growth, I had increasingly grown lonely for whom I would come to understand as my people, which is “similar to the African idea of ‘ubuntu”, as “I find myself in you” (McNiff, 2013, p.51).

As a consequence of moving away, and then gradually returning to my preferred and familiar people and subject matter, I understand the true meaning and benefits of suspended learning (Pitt & Britzman, 2003). By converging with theories and beliefs outside of typical autism discourse, I have come to more deeply understand psychoanalytic theories of listening presented by Todd (2003) and acceptance of Otherness presented by Ahmed (2002); and how these emancipatory actions are relevant to co-creating knowledge with autistic people in research and education. I also understood the commensurability between anti-oppressive research in Indigenous, feminist and LGBTQ research and critical disability research, specifically autism research. Consequently, this realization of sameness prompted me to explore humanism, critical posthumanism, and critical disability studies. Where theories of humanism are conceptualized as a rigid construct representing binary categories of ability and disability based on mind-body connectedness, perfection, and individualism (Dolezal, 2017; Goodley et al., 2016), critical posthumanism moves beyond the either/or of humanism and posthumanism to include an “array of different posthuman perspectives” (Braidotti, 2016, p.14). Critical disability aligns with critical posthumanism because both contests socially constructed theories of human experience, including theories of ableism (Saur & Sidorkin, 2018); where ableism is described as the beliefs and practices society use to devalue and limit persons with disabilities (Stop Ableism, 2019). My introduction to the study of humanism, critical posthumanism, and critical disability studies
served as a catalyst for returning to my familiar position of autism ally, however with more mature ontological and epistemological lenses.

My return to autism and disability literature began by searching terms such as the history of autism, non-speaking, identity first perspectives, autistic students’ school experiences, ableism, and critical disability theory. I additionally drew on activist blogs, social media posts, videos, and open access publications. There are several prominent autism scholars and activists I revisited as they provided insider perspectives on social, medical, and research discourse and their perspectives frequently challenged my philosophical stances on the recognition and non-recognition of autistic people. To name a few, these passionate and instrumental people include Dr. Dora Raymaker from Portland State University, independent UK researcher Dr. Dinah Murray, and self-advocates Jim Sinclair, Mel Baggs, and Ido Kedar. Finally, I used inductive questioning to recursively explore interconnected macro and micro factors contributing to the current lack of autistic voice in research and education. Where deductive questioning assumes the truth of an answer to be exact, inductive questioning assumes the truth of an answer to be possible (Cohen et al., 2006), which aligns with the exploratory nature of this research.

**Historical Perspectives on Theories and Treatment of Autism**

The purpose of revisiting the history of autism is to explore how humanist theories of ability and difference have categorically excluded autistic Otherness from humanity (Goodley et al., 2014; Goodley et al., 2016). There are limitations to presenting history in a linear fashion because there is a risk of representing knowledge in repetitive ways, which may reinforce singular and biased perspectives (Pitt & Britzman, 2003; Ellsworth, 1997). While I provide names and dates of people and their contributions in a sequential manner, I also consider a separate sub-section titled Researchers in Context, the broader conditions in which these theories
were conceived, namely Nazi Germany. The identification and treatment of autistic individuals do not occur in a vacuum but is affected by evolving social, political, and scientific factors. By revisiting and re-examining such factors, the opportunity exists to deepen our awareness of the beliefs and actions that have led to the non and misrecognition of autistic people and the subsequent exclusion of autistic voice in research and education.

Though I mainly focus on Western and European researcher perspectives from the nineteenth century, it is noteworthy to mention that accounts of autistic-like characteristics have been recorded as early as the eleventh century. For instance, it is recorded that St. Francis of Assisi (1181-1226) tells a story where Brother Juniper cuts off a pig’s foot as a literal interpretation of an act of charity (Trevett, 2009). Additional accounts describe Brother Juniper as being naïve and lacking social intuition (Wing, 1997). In the eighteenth century, Jean-Marc Itard, a French physician famously known for taking in a feral boy named Victor, described as having social impairments and unusual behaviour such as spinning and rocking (Swinton & Trevett, 2009; Wing, 1997). These early accounts exemplify long-standing European conceptualizations and evaluations of normative and non-normative behaviours, demonstrating our deep-rooted tendency to categorize people in response to difference.

1910: Eugen Bleuler

The history of autism is commonly presented with the work of Eugen Bleuler, who, in 1910, described the concept of autism as a withdrawal from the external world and a symptom of schizophrenia (Greydanus & Toledo-Pereya, 2012; Verhoeff, 2013). Bleur’s definition of autism, based on the derivative of the Greek word “autos” meaning self (Merriam-Webster, 2020), reflected a different way of thinking observed in autistic individuals (Frith, 1991). Bleur’s
theories on autistic thinking called into question the legitimacy of humanness in relationship to the psyche and linked medicalized definitions of ability and disability to autism.

1938: Hans Asperger

Austrian, pediatrician, eugenicist and medical professor Hans Asperger published research on what he termed autistic psychopathy (Frith, 1991). Asperger’s description of autistic characteristics included “a lack of empathy, little ability to form friendships, one-sided conversations, intense absorption in a special interest, and clumsy movements” (Attwood, 1997, p. 11). Asperger also noted literal-mindedness, anxiety, high speaking ability and, in some instances, intellectually giftedness (Bergenmar et al., 2015). Eventually, the term high functioning autism became synonymous with Asperger’s syndrome. In one of Asperger’s 1939 case studies, Asperger describes interactions between a boy and his mother. Anchoring a portion of his analysis on his belief that women are usually more “emotional than intelligent” (Frith, 1991, p. 41), Asperger concludes that the boy and his mother were equally strange. While Asperger’s work remained mostly unnoticed in the English-speaking world until it was translated from German to English by Lorna Wing in the 1980s (Wing, 1981), his observations reflected hegemonic definitions of humanity in what Braidotti (2013) describes represents a “male of the species: it is a he. He is white, European, handsome and able-bodied” (p.24).

1943: Leo Kanner

In 1943 Austrian-American psychiatrist and physician Leo Kanner introduced a new psychiatric condition called early infantile autism (Verhoeff, 2013). Interestingly, one of Asperger’s chief diagnosticians, Viktor Frankl, immigrated to the United States of America and was hired by Kanner in 1937 (Silberman, 2015). Therefore, it can be assumed that Kanner’s work was influenced in part by Asperger’s early research on autism in Vienna. Kanner distanced
himself from Bleur’s theories of autism (as being a feature of adult schizophrenia) instead, believing autism to be a psychobiological disorder influenced by biological, psychological and social factors (Eisenberg & Kanner, 1956, p.564). Kanner’s research described autistic children as having:

an extreme autistic aloneness ... [a] limitation in the variety of spontaneous activity...
performances [and verbal utterances that] are monotonously repetitious ... the child’s behavior is governed by an anxiously obsessive desire for the maintenance of sameness ...
[the child has] excellent rote memory (Kanner, 1943, pp. 242-243).

As a result of Kanner’s research, the boundaries of autism expanded to include language and cognitive abnormalities (Verhoeff, 2013). Kanner’s theory on the psychobiological origins of autism also inferred controversial parental causation theories, including maternal coldness and a lack of affection (Eisenberg & Kanner, 1956; Kotsopoulos, 2014). In 1948, Time Magazine published an article on Kanner’s work titled “Medicine: Frosted children” (Time Magazine, April 26, 1948) describing autistic children as “diaper-aged schizoids” and their parents as “cold perfectionists” (Time, 1948, para. 3; Waltz, 2005). Time Magazine concluded their article with the question, “Were the cold parents freezing their children into autism?” (Donavan & Zucker, 2016, p. 79). Thus, inferring parents, subsequently known as “refrigerator mothers” (Donvan & Zucker, 2016, p. 88), were responsible for causing their child’s autism. The broad psycho-social impact of Time Magazine’s indiscreet publication on families, particularly mothers of autistic children, was oppressive and harmful. Not only were families publicly blamed for their child’s perceived abnormalities, but mothers were also expected to undergo psychotherapy as part of their child’s remediation (Chamak, 2008; Kotsopoulos, 2014).
Kanner’s inclusion of language and cognitive differences in identifying autism served to more precisely and consistently exclude autistics from normative categories. Autistic children were commonly categorized according to their “devalued difference” (Goodley et al., 2014, p. 347) or strange ability; either way, they deviated from normative categories of human functioning (Saur & Sidorkin, 2018).

1967: Bruno Bettelheim

In 1967, Austrian-American Bruno Bettelheim published an article titled “Infantile Autism: The birth of self” (Bettelheim, 1967). In it he writes of a boy whom he describes as a “boy-machine” (p. 235), “a robot” (p. 236) and a “machine powered body” (p. 261) who has built up his defences to protect himself from his “refrigerator mother” (Zager et al., 2012, p.4). Bettelheim’s theories on autism have not been substantiated by standardized medical or psychological tests (Waltz, 2005) and have since been discredited based on evidence of falsification of academic credentials, plagiarism, and the mistreatment of children (Greydanus & Toledo-Pereyra, 2012). While Bettelheim’s contributions to theories and treatment of autism have been discredited, history cannot unknow his philosophies and the fact that they represented extreme and sometimes violent theories of ability and difference.

Autism Researchers in the Context of Nazi Germany

As previously mentioned, autism theories do not exist in a vacuum but instead, live in relation to broader social and political contexts. Hence, it is relevant to draw attention to the influential and questionable social and political context of Asperger, Kanner and Bettelheim’s life experiences and how they may have contributed to modern ideas and treatment of autistic people. For instance, all three men were born in Austria between 1894 and 1906. Kanner and Bettelheim were both Jewish, and Asperger was of German descent. Kanner and Asperger each
served in the German army with Kanner serving in World War I and Asperger serving in World War II (Neumärker, 2003). Bettelheim was imprisoned for ten months in a concentration camp, and after the war, both he and Kanner immigrated to the United States (Greydanus & Toledo-Pereyra, 2012). Additionally, both Asperger and Bettelheim reportedly censored parts of their histories to protect and legitimize their professional identities. For instance, Asperger was accused of sending disabled children to be euthanized during World War II (Hippler & Klicpera, 2003; Scheffer, 2018), and Bettelheim misrepresented his background and credentials to secure professorial and director positions at Universities (Pollack, 1997).

In her book titled *Asperger’s Children: The Origins of Autism in Nazi Vienna*, Scheffer (2018) highlights the Third Reich “as a diagnosis regime… obsessed with sorting the population into categories, cataloguing people by race, politics, religion, sexuality, criminality, heredity and biological defects” (p.18), which ultimately shaped Asperger’s theory of autism. In addition to Sheffer (2018), other scholars have questioned the legitimacy of society’s reverence for the patriarchs of autism. As more publications become translated to English, evidence emerges that autism research existed before Asperger and Kanner’s work. For instance, it has been suggested that Asperger may have known about a female Russian scientist, Grunya Sukhareva’s 1925 publication describing features of autism that are very similar to current DSM-5 descriptions of autism (Zeldovich, 2018). However, Asperger may have avoided crediting Sukhareva’s work not only because she was female but also because she was Jewish, and thus, recognition was most likely not permitted by the Third Reich (Zeldovich, 2018). Without dispute, Europe’s political and social landscape during the first half of the 21st century was fraught with conformist ideologies, ostensibly influencing subsequent and current scientific beliefs on difference, disability, and humanity.
Parent Perspectives on Theories of Disability and Inclusion

Until the 1960s, medical theories perpetuated ideas that equated difference with a deficit, and many parents were led to believe that an autism diagnosis was a tragedy. Feelings of guilt and loss coupled with questions about the future led to chronic levels of stress, isolation, depression, and in some cases, a diagnosis of post-traumatic stress disorder (PTSD) (Chamak, 2008; Kotsopoulos, 2014). While parents no longer participated in therapy to remedy their autism inducing tendencies, many parents sought therapy to help cope with the complex challenges associated with parenting an autistic child. Parent-scientists held a unique insider position that gave them an advantage in navigating and challenging the medical system from within. For most parents, autism was not a “decontextualized ‘thing’ discoverable by science” (Verhoeff, p. 444), but a misunderstood and unappreciated feature of their child.

1965: Parent Advocacy

In 1965 Ruth Sullivan, who was told her son’s autism resulted from the lack of bonding during infancy (Zager et al., p. 5, 2012), partnered with parent Bernard Rimland, a research psychologist, and former student of Kanner. Together they established what is now recognized as the Autism Society of America (ASA) (Kirkham, 2017), which aims to increase public awareness and advocate for persons with developmental disabilities and their families (Autism Society, 2018). Rimland challenged Kanner’s theories of parental causation (Donvan & Zucker, 2016) in his book Infantile Autism (1969). It is here where Rimland theorized autism to be an organic disorder (not a mental or emotional problem) triggered by a confluence of genetic and environmental factors (Frith, 2008; Krause et al., 2002). Two years later, in 1967, Rimland established the Autism Research Institute (ARI), which created the now disbanded “Defeat Autism Now!” project that supported the discredited belief that vaccines were a cause of autism.
(Eyal et al., 2010). Rimland’s opinions in the autism community were antithetical because while he opposed parental causation theories, he defended that autistic people should remain institutionalized in his publication titled “BEWARE THE ADVOZEALOTS: Mindless Good Intentions Injure the Handicapped” (Rimland, 1993).

In 1967 a British study reported three-quarters of several dozens of autistic individuals were institutionalized in Britain (Donvan & Zucker, 2016). Institutionalized care was recommended by doctors, suggesting that for a severely autistic child to become less autistic, they should be removed from the influences of parents and home (Chamak, 2008; Chomer, 2014). Like many other institutionalized children with disabilities, autistic children experienced experimental and discriminatory treatment, including lysergic acid diethylamide (LSD). This hallucinogenic drug causes alterations in thoughts, feelings, and awareness, including seeing and hearing things that do not exist (National Institute of Drug Abuse, 2016). Researchers hypothesized that LSD treatments would promote speech, and electric shock treatments would reduce problem behaviour in autistic children (Kirkham, 2017; Sigafoos et al., 2007). In one disturbing account, electric shock was used “To give [a child] something to be anxious about, [they are] taken to the shock room” (Author Unknown, 1965, p.90). Judge Rotenberg Center is a special needs residential and day treatment program in Massachusetts, USA, where some children with severe developmental disabilities and emotional-behavioural disorders received aversive therapy; in the form of shock-based treatments (Kirkham, 2017). Students wore specially designed “machines that the students carry in backpacks worn around the clock. Wires run from the boxes to electrodes attached to the skin of student’s arms, legs or torsos” (The Guardian, 2018, para. 13). While the school defended that electric shocks pose “no serious risk to children” (The Guardian, 2018, para. 10), many human rights and disability advocates have
called for a ban on such practices, including the Autistic Self-Advocacy Network (ASAN, 2018). An outcome of ASAN’s work and other advocates, the use of electric shock on disabled students, has been banned by the United States Food and Drug Administration (FDA) as of March 2020 (Plater, 2020).

The deinstitutionalization of children was strongly influenced by lobbyists’ work, including Sullivan, who defended that all children had a right to an education (Donovan & Zucker, 2016). Historically if a child was considered *ineducable* a school jurisdiction had the authority to refuse education. Sullivan was one of the lobbyists for *The Education for All Handicapped Children*, now known as *The Individuals with Disabilities Education Act* (IDEA) (Wood, 2016). Eric Schopler, a German-American psychologist, opposed such limiting beliefs, arguing that autistic children were educable, and parents played a central role in their child’s education (Donvan & Zucker, 2016). Although Schopler was not a parent of an autistic child, he was a close and avid parent ally. Schopler is most known for the co-development of an education program for autistic students called *Treatment and Education of Autistic and Related Communication Handicapped Children* (TEACCH) (Schopler & Reichler, 1971). The TEACCH program’s effectiveness has become well recognized and respected for its student-centred approach, which provides personalized instruction based on the identification of student strengths (Chamak, 2008; Mesibov & Shea, 2010). The TEACHH program represented a shift in beliefs regarding non-normative ability and possibility for autistic students from both the scientific and educational communities.

Scientist-parent Rimland’s research and advocacy work overlapped with clinical psychologist Ole Ivar Lovaas from UCLA. Lovaas who was a co-founder of the ASA, also believed that autistic children could be taught *normalized* behaviours by using Applied
Behavioural Analysis (ABA) (Buch & Lovaas, 1977). Theories of ABA arose from behavioural psychology from the 1910s (Kirkham, 2017) and was first used to condition animals’ behavior, as famously recognized in the work of B.F. Skinner (Kirkham, 2017). Principles of behaviourism were first applied to autistic children in the 1960s where researcher Ferster (1961) “locked an autistic child in a room daily for a year. He refused to attend to the child when it cried, and its tantrums stopped” (Kirham, 2017, p.110). Lovaas continued the work of Ferster and reported that when autistic children received a minimum of 40 hours per week of ABA therapy, approximately 47% achieved normal functioning, 43% made significant progress, and 10% made little progress (Sallows & Graupner, 2005; Kirkham, 2017). However, researchers have disputed these findings arguing a weak methodology, insignificant effect sizes, and that there were no statistically significant differences between outcomes of students who participated in special education programs for non-speaking students and those who participated in the Lovaas method (Ospina et. al., 2008). Lovaas’ ABA program was made available to parents through his book *Teaching Developmentally Disabled Children: The Me Book* (Lovaas, 1981) but was criticized by other scientists and parents for the inhumane use of aversives, also called punishments for incorrect responses made by autistic children (Kirkham, 2017). While many questioned the ethical treatment of autistic children who participated in ABA programs, some saw the program as a lesser of two evils. Some autistic children and adults can exhibit Self-Injurious Behaviour (SIB), such as eye-gouging and headbanging. Parents feeling helpless and unable to protect their children from conditions causing their children to self-injure, opted for intensive Lovaas ABA intervention, which included the delivery of aversives, such as electric shock, to reduce SIB. While less intense versions of Lovaas’ early ABA programs continue to be used worldwide, ABA methods are frequently met with mixed responses. First and foremost, many autistic self-
advocates consider ABA pedagogy to be abusive, unethical (Chamak, 2008; Gruson-Wood, 2016; Socially Anxious Advocate, 2015) and that it “takes away our voice” (Bascom, 2012, p.182). Ido Kader, a non-speaking young autistic man, recalls ABA therapy as a time of suffering and that he continues to get PTSD flashbacks just hearing the phrases, “High Five!” or “Good Job!” (Kedar, 2018, para. 2). Secondly, many researchers and scientists continue to believe the benefits of ABA have been exaggerated (Fernell et al., 2015; Weiss & Delmolino, 2006) and that initial claims of effectiveness and cure have not been replicated (Matson & Neal, 2012).

1970: Parents Backed by Research

Lorna Wing, a British mother of an autistic child, psychiatrist and epidemiologist, published one of the first books for parents of autistic children titled Autistic Children: A Guide for Parents (Wing, 1971). Wing also helped establish the National Autistic Society in the United Kingdom to provide schooling and residential care to autistic children (Donavan & Zucker, 2016). In addition to completing the first epidemiological studies on autism, Wing was primary in having Asperger’s research papers translated from German to English, which provided the basis for considering autism as a spectrum condition rather than isolated disorders in the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV). Through Wing’s work, Asperger Syndrome became popularized to label individuals with average to above-average intellectual function but had social, linguistic and sensory processing (Verhoeff, 2013). As a result of translating and extending Asperger’s research and completing the first large scale epidemiological study, Wing’s research broadened the categorization of autism to include a spectrum of abilities rather than isolated disorders (Frith, 2003; Verhoeff, 2013). Wing’s research introduced the concept of triad of impairments, which suggested impaired social,
communication, and cognitive flexibility as representing the core characteristics of autism (Wing & Gould, 1979). Uta Frith, a student of Wing’s and a mentor to currently influential autism researcher Simon Baron-Cohen, co-published the first article examining autistic ability and theory of mind (ToM), proposing that autistic individuals have difficulty understanding other people’s implicit beliefs and desires (Baron-Cohen et al., 1985). Frith also suggested that autistic individuals have weak central coherence in that they are more able to process detailed information but cannot integrate detailed information into an integrated gestalt (2003). Frith contested ideas that autism resulted from cold parenting, as suggested by Kanner and Bettelheim, but like Rimland, suggested that autism was rooted in biology. In response to the advocacy of parent-scientists, Kanner eventually responded to the popular refrigerator mother theory suggesting he was misquoted, thus absolving parents of their role in influencing the expression of their child’s autism (Donvan & Zinker, 2016). A summary of the historical perspectives on autism is provided in Appendix A, titled Timeline of European and Western Historical Perspectives.

**Identity First Perspectives on Autism, Ability and Inclusion**

**Autism Diagnosis**

According to medicalized definitions, Autism Spectrum Disorder (ASD) is considered a life-long neurological disorder caused by complex interactions between genetic and environmental factors (Ornoy et al., 2015). The current Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) specifies that people diagnosed with autism have impairments in:

a) Social communication and social interaction;

b) Restricted, repetitive patterns of behaviour, interests or activities;
c) Symptoms must be present in early childhood but usually do not fully manifest until social demands exceed limited capacities; and
d) Symptoms together limit and impair everyday functioning (American Psychological Association [APA], 2013).

Like all people, no two autistic people are alike and have varying strengths in communication, social, and behavioural skills (Carter & Scherer, 2013). While there is a significant increase in autism diagnoses, some researchers defend that “diagnostic recategorization toward autism is occurring, potentially confounding estimates of autism prevalence” (Navon & Eyal, 2016; Polyak et al., 2015). For example, Polyak et al. (2015) reported that autism diagnoses have increased in the United States of America by 331% between 2000 and 2010, while diagnoses related to intellectual disabilities decreased 31%, emotional disturbances decreased 22%, and learning disabilities decreased 19% (Waterhouse et al., 2016). If epidemiological estimates correctly identify 1.5%-1.8% of the population as autistic, then more accurate identification of neurological features, including intellectual disability, is being overshadowed by the over-inclusivity of autism (Lundström et al., 2015). In the context of education, this diagnostic overshadowing potentially impacts student programming, including selecting appropriate supports and strategies to ensure students’ academic and social success.

People diagnosed as autistic frequently have co-occurring conditions, including attention deficit and hyperactivity disorder (ADHD), anxiety, depression, seizures, gastrointestinal issues, and sleep disturbances (Baron-Cohen et al., 2014). Co-occurring conditions such as these put additional stressors on autistic people, further complicating the accuracy of an autism diagnosis which exclusively relies on behavioural observations. An autistic individual’s complex and variable interaction between biology and environment over the lifespan, coupled with intense
efforts from outsiders to remediate, places significant amounts of stress upon the autistic individual. Up to 65% of autistic adolescents experience anxiety and depression (Attwood, 2004), and 1/300 have contemplated or engaged in self-harming behaviour (Marshall et al., 2015). Autistic people are also “nine times more likely than the general population to die by suicide” (den Houting, 2020, p.1). Like most adolescents, autistic individuals desire meaningful peer relationships (Williamson et al., 2008). However, they have fewer friendships than non-autistic peers (Locke et al., 2010; Mazurek & Kanne, 2010) and report more loneliness than non-autistic peers (Locke et al., 2010).

Autobiographical accounts on the pressures of having to *act normal* have been shown to negatively impact an autistic person’s acceptance of self and development of a positive identity (Humphrey & Lewis, 2008). As a result of being assigned various diagnostic labels and treatment programs, views that equate difference with deficit becomes impressed upon an autistic individual early on in their development. However, in recent years more autistic people are sharing insider perspectives on theories of autism, remediation and cure, which benefits autistic people and their allies by challenging ableist beliefs and practices that protect notions of normality and human ability.

**Autistic Self-Advocacy**

The Autistic Self-Advocacy Network (ASAN) is a non-profit organization established by and for autistic persons. Their mission is to advocate for the inclusion of autistic voice in matters related to public awareness and policy through their motto “nothing about us, without us” (ASAN, 2018; Charlton, 2000). ASAN publicly protests one of the most prominent autism advocacy agencies in America, called Autism Speaks. Historically, ASAN has criticized Autism Speaks’ support for traditional ABA therapies (Kirkham, 2017), a mission to cure autism, and
funding research in the scientifically discredited belief that vaccines cause autism. Lydia Brown, autistic author and advocate from ASAN shares her perspective on how language shapes her identity and recognition of her autistic Otherness:

…when we say “Autistic person,” we recognize, affirm, and validate an individual’s identity as an Autistic person. We recognize the value and worth of that individual as an Autistic person — that being Autistic is not a condition absolutely irreconcilable with regarding people as inherently valuable and worth something. We affirm the individual’s potential to grow and mature, to overcome challenges and disability, and to live a meaningful life as an Autistic. Ultimately, we are accepting that the individual is different from non-Autistic people—and that that’s not a tragedy, and we are showing that we are not afraid or ashamed to recognize that difference (Brown, 2011, para. 18).

In the study titled “Which terms should be used to describe autism? Perspectives from the UK autism community” (Buckley et al., 2015) researchers surveyed autistic people, parents, and professionals to better understand their preferential use of person-first or identity-first language. Respondents included 502 autistic individuals, 1,666 parents/caregivers, and 967 professionals via an online survey. Results show that most autistic persons prefer identity-first language, and parents and professionals prefer to use person-first language (Buckley et al., 2015). Research cited in the same study supports autistic preference for identity-first language because autistics defend that autism is not a disease, but an essential part of their identity (Bagatell, 2010; Davidson & Henderson, 2010). Furthermore, autistic people sought to be included in normalized linguistic rules where “positive pronouns should precede nouns” (Buckley et al., 2015, p.2). Autistic participants expanded on their preference for identity-first language by sharing the following:
I understand the 'I am a person with autism', but I would never say 'I am a person with brown hair'. I would say, 'I'm a(n) aspie/autistic’ or 'I'm a brunette'. Separating the person from their autism is damaging, as it reinforces opinions about autism being a 'thing’ that can be removed, something that may be unpleasant and unwanted, and something that is not just another aspect of a whole, complete and perfect individual human being. Describing oneself as autistic is an extremely important and positive assertion about oneself, it means that one feels complete and whole as one is (Buckley et al., 2015, p.7).

Opposingly, parents defended that the person should come first, not their diagnosis (Buckley et al., 2015, p.9) and reasoned that “the person with autism is a person-first and their condition second” and that “we need to describe the individual and ASD as separate entities with the emphasis on the individual not the disorder” (Buckley et al., 2015, p.10). Although professionals also preferred person-first language, they tend to consider the use of language in context. As one professional stated:

When talking to families, I would be very careful not to use certain phrases or labels as I feel this takes away the individuality of each person. When dealing with professionals in other agencies, I would use certain ‘phrases’ to start to guide expectations of the abilities of a person, but always reinforced by the individual complexities and abilities (Buckley et al., 2015, p.12).

While the debate on the appropriate use of identity-first versus person-first language continues, opportunities exist within these spaces to explore how the use of language shapes our “social and ideological beliefs about autism” (Buckley et al., 2015, p.2) and through a critical disability theory framework, protects positions of authority and power over autistic people.


**Autistic Identity**

Canadian philosopher Charles Taylor (1992) discusses the oppressive and harmful impact of non-recognition and misrecognition on individual identity formation. Taylor defends that when society perpetually echoes beliefs of deficit, inability and fault onto people, the idea of the self as belonging to humanity becomes distorted (1992), often leading to “internalised oppression” (Barnes & Oliver, 2012, p. 111). As a result of the non-recognition and misrecognition of autistic Otherness as a legitimate way of being human, autistics may question their sense of belonging. Autistic individuals’ perceived lack of social competence and repeated rejection of authentic self contributes to higher reports of anxiety and depression in the autistic population compared to the non-autistic population (Cage et al., 2018; Chandrasekhar & Sikich, 2015).

Taylor goes on to state that the formation of identity is dialogical, in that we use language to understand ourselves and to form our identities (1992). However, in contrast to the previously referenced humanist theory that characterizes oral speech as a representation of reason and identity (Bergenmar et al., 2015; St. Pierre, 2015), Taylor’s concept of language is described as “not only the words we speak, but other modes of expression whereby we define ourselves, including the languages of art, gestures, of love, and the like” (p.32). Autistic self-advocate, Amanda Baggs (2012) echo’s Taylor’s concept of language by communicating through her body and through gestures and calls this “the language we already spoke fluently before we learned that words existed, it requires innate, prolonged knowledge of a way of experiencing the world that most people aren't aware of” (p.14).
Autistic First Voice: Speaking and Non-speaking Communication

Contemplating the concept of first voice in relation to speaking and non-speaking autistic individuals presents an interesting paradox. Current DSM-5 criteria outline that in addition to restricted and repetitive behaviours, autistic individuals have “persistent deficits in social communication and social interaction across multiple contexts” (American Psychological Association [APA], 2013). Deficits in social communication skills include idiosyncratic, repetitive and non-use of speaking language. The severity of behavioural and communication deficits ranges from mild, moderate to severe and are assigned Levels 1, 2 or 3, respectively. St. Pierre (2015) proposes that humanist and posthuman theories view speech as an “enactment of reason and therefore of human identity” (p.332). Applying St. Pierre’s theory against autism diagnostic criteria, autistic individuals would presumably have a limited or null identity dependent on their speaking ability and diagnostic severity level. Foundations of posthuman theory are found in current diagnostic tools, including the DSM-5, used to identify individuals as typical or atypical. Posthuman views on levels of humanness are not only evidenced by the assignment of autistic severity (Levels 1, 2 or 3) but also in the terms used to describe autistic features; including deficit, delayed, impaired, odd, limited, failing, and abnormal (Centres for Disease Control and Prevention, 2018).

St. Pierre (2015) contemplates the correlation between an individual’s speaking ability and capacity to reason; he frames the tension as such: “oral speech has occupied a dignified position within the humanist lineage, shaping central questions on what it is to be human” (p. 330) and that this modern invention has had “exclusionary consequences” (p. 330). As oral speech has become a privileged representation of reasoning ability (Bergenmar et al., 2015; St. Pierre, 2015;
Tisdall, 2012), non-speaking autistic voice is frequently ignored, and when listened to, the authenticity of experience and modes of representation are called into question.

Abilities of autistic individuals are commonly measured against standardized cognitive, speech, and motor assessments that are normed on non-autistic ways of being, including thinking, moving and communicating; consequently, “underestimating or overlooking” (Zeliadt, 2018, para 5) autistic ability and intelligence. Coupled with designating autism severity levels, clinicians assign what Bergenmar et al. (2015) call subtypes of humanness.

In his blog post titled “The 3P’s of communication skeptics” (2018b), Kedar shares a similar message stating: “Non-speaking does not mean non-thinking. That’s my mantra. Non-speaking may be caused by motor issues. That’s my message. Motor issues do not cause stupidity. That’s my point.” (para. 1). Kedar goes on to specifically address professionals working in the field of autism, stating:

There is an overwhelming need for professionals to learn about autism from those who live it and can describe it in words. I am referring to the non-speaking typer who tries to explain autism from the inside out. There are now quite a few of us, and the number is growing. Our messages are always the same. Intact mind/disobeying body. Smart head/dumb body. Thinking mind/non-thinking motor system. Not speaking is not the same as not thinking (2018a, paragraph 2).

Non-speaking autistic self-advocates challenge posthuman assumptions that equate intelligence with speaking and motor ability and prove that non-verbal speech embodies authentic, vibrant and ordinary experiences (Palen, 2014). Thus, my rationale for not separating and subsequently comparing data sets between speaking and non-speaking participants is guided by the advocacy work of autistic people and understanding the potentially harmful impact on the autistic
community. However, while contrasting the experiences of subgroups of marginalized people may be productive in some instances, careful attention to avoid object reduction must occur, which might imply ranking or exclusion from the *normal* human domain (Goodley et al., 2014; Mladenov, 2014). One-way researchers might avoid object reduction is to use a participatory research approach where autistic people would be equal partners in developing the research question, designing research protocols, collecting and analyzing data, and presenting findings (Benford & Standen, 2011). Ethical research practices such as this help challenge researchers to shift their “scientific gaze” (Scott-Barrett et al. 2019, p.177) from practices that perpetuate ideas that autism is pathological.

**Augmentative and Alternative Communication (AAC)**

Between 25% and 30% of individuals diagnosed with autism are non or minimally speaking (Kasari et al., 2014; Tager-Flusberg & Kasari, 2013). The use of alternative modes of communication can be traced back to sixteenth-century Europeans and First Nations peoples of North America (Wurtzburg & Campbell, 1995). Early Europeans used sign language to communicate with the deaf, and Indigenous people used forms of manual and pictorial language to communicate with tribes who spoke different languages (Wurtzburg & Campbell, 1995). The development of technology based AAC devices began in the early nineteenth century to support individuals with severe physical disabilities, specifically those with cerebral palsy (Vanerheiden, 2002). Transferring assistive communication principles to the autistic population did not occur until the 1960s, where communication boards were used with children using early methods of applied behaviour analysis (Donvan & Zucker, 2016). The United Nations Convention on the Rights of Persons with Disabilities (2018) defines AAC as methods used to facilitate speech and written communication, including sign language, picture symbols, large print, tactile
communication, plain language, multimedia, and technologies such as speech generating devices.

For individuals who are considered intelligible (Bergenmar et al., 2015), the use of generated speech allows non and minimally speaking individuals to interact with others. Applying Foucault’s (1982) theories on how experiences are legitimized, tools such as AAC legitimize autistic experience through speaking language. AAC methods create positive and welcomed opportunities for non and minimally speaking autistic individuals to communicate their feelings, needs, thoughts, and experiences with loved ones and social groups. While AAC provides emancipatory opportunities for autistics to connect with others and verify their selves as intelligent and rational human beings, it is important to recognize the restrictive posthuman structures that underscore several features of AAC devices. For instance, for a non or minimally speaking autistic person to enter dialogue using an AAC, they are first expected to conform to implicitly governed non-autistic speaking modes of address (Ellsworth, 1997). Pre-programmed symbols, pictures and vocabularies predominantly reflect societal preferences for conversational topics and experiences. If an autistic individual wanted to share an experience outside of non-autistic boundaries, such as how he “sees” his mother’s voice (Higashida, 2016, para 6), the opportunity might not exist, or the legitimacy of their experience would be called into question and subsequently corrected as a result of non-autistic experience and dissonance. Subsequently, authentic expression of autistic experience and, by extension, autistic Otherness becomes unrecognized or muted.

While the primary goal of AAC is to facilitate efficient and effective communication (Beukelman & Mirenda, 2005) and to provide opportunities for non and minimally speaking autistic individuals to share their experiences; the use of AAC also has the potential to decontextualize the autistic individual from their authentic experiences and selves (Taylor,
Replacing biological communicative preferences with ableist methods risks disconnecting autistic individuals from the authentic ways they represent experiences to themselves and others. Over time, through repeated mis or non-recognition, communicative biology may be replaced with socially preferred communicative behaviours, essentially denying the authentic self to be viewed as so-called typical (Bergenmar et al., 2015). Thus, the burden of conforming to dominant modes of address (Ashby & Causton-Theoharis, 2009) as well as self-translating experience into “textual thoughts” (Bergenmar et al., 2015, p. 213) is unevenly placed on the non or minimally speaking autistic person.

Naoki Higashida, a semi-non-speaking autistic teenager from Japan, published the book *The Reason I Jump* (2016). The original version was published in Japanese in 2007 and has since been translated into thirty languages (Mitchell, 2017). Like many other speaking and non-speaking autistics who have learned to communicate using AAC, Higashida’s reflections on voice and identity are central themes to his writings. Through question and answer format, Higashida shares his personal experiences of being autistic. Although Higashida describes many challenging experiences, which cause periods of sadness, shame and loneliness, his sharp answer to the question “Would you like to be “normal?” helps destabilize authoritative stances on normativity, cure and conceptions of a meaningful life:

What would we do if there was some way that we could me “normal”? Well, I bet the people around us-our parents and teachers-would be ecstatic with joy and say “Hallelujah! We’ll change them back to normal right now!” And for ages and ages I badly wanted to be normal, too. Living with special needs is so depressing and relentless; I used to think it'd be the best thing if I could just live my life like a normal person.
But now, even if somebody developed a medicine to cure autism, I might well choose to stay as I am. Why have I come around to thinking this way?

To give the short version, I've learned that every human being, with or without disabilities, needs to strive to do their best, and by striving for happiness you will arrive at happiness. For us, you see, having autism is normal-so we can't know for sure what your “normal” is even like. But so long as we can learn to love ourselves, I'm not sure how much it matters whether we’re normal or autistic p. 45).

Higashida answers several more questions that respond to ableist expectations of legitimate communication, including: “Why do you ask the same questions over and over?” (p.10) “Why do you take ages to answer questions?” (p.18), “Should we listen to every single word you say?” (p.19), and “Why can't you have a proper conversation?” (p.21). To the last, Higashida’s (2016) responds with:

Please don't judge us from the outside only. I don't know why we can't talk properly. But it’s not that we won’t talk-it’s that we can’t talk and we are suffering because of it. All on our own, there’s nothing we can do about this problem, and there were times when I used to wonder why Non-Speaking Me had ever been born. But having started with text communication, now I'm able to express myself via the alphabet grid and a computer, and being able to share what I think allows me to understand that I, too, exist in this world as a human being (p.22).

Expected and preferred communicative criteria founded in ableist constructs of time, reciprocity, and procedure are reflected in vocabulary such as “a proper conversation” and exemplify a sampling of the many communicative barriers autistic people are faced with. Higashida’s
introspective abilities and clarity of thought are evident, as are the deep-rooted prejudices that he is expected to overcome to be considered a rationally able human.

Similar to the intense levels of scrutiny experienced by other marginalized groups, including women and racial minorities, the authenticity of Higashida’s writings has been called into question by both abled and disabled skeptics, including well known autistic Temple Grandin. The controversy specifically relates to the method of facilitated communication, where individuals receive motor support for their typing through gentle arm and hand touches (International Society on Augmented and Alternative Communication (ISAAC), 2014; Mitchell, 2017). The scientific community defends that the facilitator, not the communicator, creates messages either in part or in full (Ganz, 2014; Montee et al., 1995; Saloviita et al., 2014). While Higashida was initially trained in facilitated communication, his typing is observed independently produced on a keyboard or a cardboard replica, which he finds less distracting. Eventually, Higashida’s writings were authenticated by Grandin in her written review (2014) of Higashida’s book.

Ido and Higashida’s experiences illustrate the tenuous position of AAC being both emancipatory and oppressive. Through self-reports, we learn of the great relief and appreciation for expressing oneself and connecting with others. We also learn that the recognition of people as both autistic and rational is often contingent on the validation of speaking, non-disabled outsiders.

A Review of Inclusive Education Policy and Practice

The concept of integration entered the educational landscape in the 1960s, in response to human rights movements that challenged segregated schooling for people with disabilities (Göransson & Nilholma, 2014). The right to appropriate and meaningful education is backed by
law including *The International Convention of the Rights of the Child* (United Nations in Convention on the Rights of the Child, 1989) and *The Convention on the Rights of the Person with Disability* (United Nations in Convention on the Rights of Persons with Disabilities, 2006). Policies to develop inclusive education policies from a global perspective are guided by what is known as the *Salamanca Statement and Framework for Action on Special Needs Education* (UNESCO, 1997). Definitions of inclusion and what it means to be included vary (Artiles et al., 2006), leading to mixed reviews of best practice. In a systematic review titled “What is meant by inclusion? An analysis of European and North American journal articles with high impact” (Göransson & Nilholma, 2017), the authors suggest that there is a “conceptual divide” (p. 447) between definitions of inclusive education, where some definitions emphasize placement or “where” (p.445) students should be, while other definitions focus on the “wellbeing” (p.445) of the student, in the context of social and academic environments. It is worthy to note that research has found that the quality of instruction versus placement of students is the strongest predictor of student achievement (Mitchell & Sutherland, 2020). Critical disability theorists assert that while the objective of integration may be to create a more inclusive society, integration is a modern form of oppression because it aims to purify and normalize through assimilation (Paterson & Hughes, 1999).

**Canadian Inclusive Education Policy.** According to a report published by the Canadian Centre for Policy Alternatives (CCPA) (Towle, 2015), a child’s right to access free education is protected by several international laws, however, “Canada has no federal legislation protecting a child with a disability’s right to inclusive education because education comes under provincial and territorial jurisdiction” (p.5). Provincial interpretation of inclusive education varies, and in some cases, is different between school boards within provinces and territories. Variation in
terms used to describe Canadian students with diverse learning needs, include: “disability”, “special needs”, “exceptional needs” and “intensive needs” (Towle, p. 10), further impacting clear definitions and practices of inclusive education. According to research conducted in the province of Alberta (The School of Public Policy, 2016) approximately 1 in 94 children in the Calgary region have a diagnosis of autism. Data collected from a survey completed by the Canadian Teachers’ Federation (Froese-Germain & Riel, 2012) found, “the average number of students with a disability per class was 3.5 students” (p.12). Surveyed students were formally identified with behavioural, mental, and physical disabilities and gifted and English/French as a second language students. Students waiting to be diagnosed or students with learning disabilities were not included (CCPA, 2015). Thus, the information provided by the CCPA confirms teacher reports that Canadian classrooms are growing in student diversity and complexity.

**Best Practices in Inclusive Education**

Research on the best practices of inclusive schools identifies the following six characteristics as being essential: 1. Committed leadership; 2. Democratic classrooms; 3. Reflective educators; 4. Supportive culture, 5. Engaging and relevant curricula; and 6. Responsive instruction (Kluth, 2003). Stakeholder views on the inclusive education experiences of autistic students are mixed. While there is a similarity between parents’ and educators’ philosophical beliefs on the benefits of inclusion, both report poor outcomes for autistic students compared to other students with developmental disabilities (Ashburner et al., 2010; Roberts & Simpson, 2016). One teacher identified barrier is problem behaviour which is known to occur as a result of the interaction between autistic student’s social-communication skills and the school environment (Roberts & Simpson, 2016, p. 1084). However, the most significant barriers impacting the positive, inclusive experiences for both teachers and students is the quality of
school leadership (Mitchell & Sutherland, 2020), a lack of teacher knowledge and training (Roberts & Webster, 2020), and the availability of resources to support the specific needs of autistic students (Lindsay et al., 2013).

Missing from these stakeholder perspectives is the inclusion of the self-reported experiences of autistic students, which are essential if educators want to improve their knowledge on how best to co-create conditions for successful inclusion (Conn, 2014; Marshall et al., 2015). Of the vast amount of autism-related research published between 2005 and 2014, more than half of the 18,490 articles retrieved are related to the field of molecular genetics (Sweileh et al., 2016). Medical research overshadows the small amounts of research that centers on autistic self-reports and frequently disregards self-published literature by autistic self-advocates. As stated by autistic writer, Ido Kedar:

In the six years since my first book, Ido in Autismland was published, only one researcher ever contacted me to learn about autism from me. That’s kind of pathetic if you think about it. I'd like to help guide their research on my real symptoms to help improve treatments and theories. A fair skeptic and inquiring scientific thinker might take the time to meet a proficient typer, to ask questions, to learn about their journey to increasing fluency. But they don't, for some reason (Kedar, 2018b, para. 3).

Kedar’s honest calling out of researchers on the lack of responsiveness and interest in seeking first-person accounts of autistic experiences confirms my research’s attentiveness and significance that sought to learn about, thus improving the inclusive education experiences of autistic students.
**Inclusive Policy and Practice: Is it Working?**

While various international organizations including the United Nations, UNICEF, and UNESCO’s Education for All, have provided countries with definitions of inclusion (Thompson et al., 2015), “no country has yet succeeded in constructing a school system that lives up to the ideals and intentions of inclusion” (Haug, 2017, p.206). This shortcoming is a dilemma between ideas and reality, where countries and educators philosophically agree with the concept of equal educational rights for persons with special education needs, however, are uncertain on how to create inclusive learning environments to respond to the unique needs of various students (Haug, 2017; Messiou, 2019; Mitchell & Sutherland, 2020). Instead, jurisdictional definitions of inclusion have become “masterpiece[s] of rhetoric” (Haug, 2017, p. 207), leading to a “political oversell” (p.207), that puts teachers in positions of unmanageability and failure. Researchers have identified several factors interfering with the unity between theories and practices of inclusive education; two examples are first, teacher confidence and competence (Domović, 2017; McCrimmon, 2015; Roberts & Webster, 2020; Tangen, 2005); and second, the increase in neo-liberal trends that value individualism, including governments who make school funding contingent on student performance (Haug, 2017). However, opportunities exist to strengthen the practical success of inclusion by combining ideals of inclusion with realities of various schools based on the perspectives of their diverse student populations.

**A Review of Autistic Students’ School Experiences**

As the prevalence of autism has increased, so has autism-related research; however, most research reflects scientist, medical, educator, and parent perspectives, or second-hand accounts (DePape & Lindsay, 2016). Furthermore, of the literature that centers on autistic students’ self-
reports, very few offer flexible methods to ensure the inclusion of non and minimally speaking autistic persons (Lebenhagen, 2019; Woodfield & Ashby, 2016).

Following, I share findings from four noteworthy studies on the self-reported school experiences of autistic students. The first two studies provide a meta-analysis of the topic from Canadian and Australian researchers; the third study is from the United Kingdom and highlights autistic students’ school experiences in the context of wellbeing. The fourth study, from the United States of America, pertains to autistic high school students who type to communicate.

**Meta-Synthesis 1.** DePape & Lindsay’s (2016) study titled “Lived experiences from the perspective of individuals with Autism Spectrum Disorder: A qualitative meta-synthesis” is based out of the University of Toronto, Canada and provides a foundational understanding of the self-reported experiences of autistic people. With 33 out of 2,892 articles meeting inclusion criteria, 17 studies explored the first-hand accounts of autistic students’ school experiences. Based on the authors’ thematic analysis of the 17 articles, seven themes are identified as essential aspects of autistic students’ school experiences: curriculum workload, boredom, transitioning, sensory issues, routines, unstructured time, and teacher understanding.

**Meta-Synthesis 2.** In a similar timeframe, Australian researchers Danker et al. (2016) published a study titled “School experiences of students with Autism Spectrum Disorder within the context of student wellbeing: A review and analysis of the literature”. Based on initial inclusion criteria, 272 journal articles were selected for review with 12 articles meeting final selection criteria and four articles specifically related to students’ school experiences. Although results were interpreted in the context of wellbeing, this analysis identified eight themes impacting the school experiences of autistic youth. The eight themes are: a) diagnostic labelling, b) relationships, c) positive/negative emotions, d) professional support, e) teacher qualities, f)
curriculum-related issues, g) environment, and h) masquerading. While the results are similar to DePape & Lindsay’s (2016) findings, where both meta-analyses identified issues with teacher and peer relationships, teacher characteristics, curriculum achievement, and environmental factors affecting sensory experiences; there are several issues identified in Danker et al. ‘s (2016) analysis that were not highlighted in DePape & Lindsay’s (2016) meta-synthesis. Including student concerns related to diagnostic labelling, masquerading of autistic symptoms, positive emotions, and depression. While these discrepancies may be attributed to the authors’ analysis of data in the context of student wellbeing, they are important considerations for educators as they evaluate responsive pedagogies to improve the school experiences of autistic students.

Mixed-Method Research: Questionnaire and Semi-Structured Interview. The study titled “Autism and the UK secondary school experience” (Dillon et al., 2016) was not included in either DePape & Lindsay’s (2016) or Danker et al. ‘s (2016) meta-synthesis but provided additional information on students’ self-reported school experiences. This mixed-methods study collected student perception data \( (n=14) \) using three questionnaires and a semi-structured interview. The results of Dillan et al.’s (2016) study identifies “four key areas that affect the quality of the school experience for students with autism: social skills, perceived relationships with teaching staff, general school functioning, and interpersonal strengths of the young person” (p. 221). While the number of participants is an identified limitation of the study, findings suggest that regardless of Westernized country, autistic students share similar concerns regarding their school experiences. Issues related to teacher support, curriculum, learning environment, and social relationships are common.

Interestingly, bullying issues are not identified as a significant theme in either of the two meta-synthesis’ or Dillan et al.’s (2016) mixed-method study. This omission is curious because
significant research exists that upholds the harmful effects of bullying on the school experiences of autistic students (Maïano et al., 2016). Furthermore, and especially relevant to this study, none of those mentioned above studies explicitly mentions the inclusion of non-speaking autistic students. The apparent absence of non-speaking autistic voice in current research further bolsters this research study’s significance and benefits.

**Autistic Students Who Type to Communicate.** The study titled “The right path of equality: supporting high school students with autism who type to communicate” (Woodfield & Ashby, 2016) was not included or referenced in any previously mentioned meta syntheses or UK study. The focus of this study by Woodfield and Ashby was to investigate the strategies and practices teachers use to support the inclusion of autistic high school students who type to communicate. Qualitative interview data were collected from students, teachers, and school personnel, and researchers completed six 80-minute observations of students in class. The first finding noted by researchers is that the success of non-speaking students is dependent on teachers making “space and time” (p.441) for autistic voice. This finding is particularly significant in the context of this research because it reinforces this study’s position on the importance of creating ethical spaces in research. Additional findings from Woodfield & Ashby’s study emphasizes the benefits of building strong relationships with teaching assistants to ensure student communication success, which includes setting up iPads and accessing printed learning materials. The study concludes by defending that flexible and coordinated teaching approaches are more effective in supporting non-speaking autistic students than educators deliberating over where non-speaking autistic students should be placed in schools.
Chapter Summary

Notwithstanding decades of research, historical perspectives on the characterizations of autism have remained unchanged until the late nineteenth century. Scientific theories on the etiology and prognosis of autism are rooted in humanist categories of normal and abnormal. However, ableist ideas and practices that regard autism as a pathological (Chamak, 2008) continue to be vigorously challenged by autistic self-advocates, parents, and allies. A dominant force in the de-institutionalization of autistic children were parent lobbyists who fought for their children’s right for school inclusion. While definitions of inclusive education are guided by several international frameworks, including the *Salamanca Statement and Framework for Action on Special Needs Education* (UNESCO, 1994), local policies to support students with disabilities are vague, which has contributed to inconsistent and ineffective inclusive education practices amongst school jurisdictions.

Consequently, this tension between the ideals and the reality of inclusive education is possibly reflected in autistic students reporting issues with curriculum, routines, school environment, relationships with teachers and peers, depression, bullying, and receiving adequate support. Most noteworthy is there is minimal research that includes the self-reported school experiences of autistic students and what is available, most reflects the perspectives of speaking autistic students. The exclusion of non-speaking student voice and perspectives is problematic because it highlights ableist practices in research, including beliefs that equate speaking voice with rational voice.
Chapter 3: Methodology

This chapter begins with an overview of my ontological and epistemological researcher perspectives and a rationale for using a critical disability theoretical framework and a phenomenologically informed research lens in this study. Also included in this chapter are a) description of the research setting, sample, and data sources; b) data collection methods and instruments; c) procedures for analysis; d) ethical considerations; e) validity, trustworthiness, treatment, and integrity; and f) limitations and delimitations of this mixed-method convergent parallel study.

Researcher Perspective

Ontologically, I believe that a person’s perceived reality is based on the interplay between their mind, biology, spirit, and external environments (Guba et al., 2018; Kapp et al., 2013); and external environments include physical, political, economic, and environmental dimensions. Epistemologically, I understand that what I know about autistic people’s experiences and how I have come to know those experiences is influenced by power differentials between abled and disabled people, which has led to the classification of disabled people based on the perceived value of human differences (Focault, 1988).

Thus, my ontological and epistemological position strongly aligns with a phenomenological lens and critical disability theory’s philosophical approaches. First, I acknowledge the diversity and dimensionality of an autistic person’s lifeworld and that autistic persons’ realities are context-specific and context-bound (Cardiff, 2012; Kajamaa, 2012). I believe that the experiences of autistic people in their own terms are valuable and can provide significant information to transform schools. Secondly, I understand that the classification and treatment of autistic people are influenced by politics and economies of perfection and power.
For this reason, critical disability theory offers a practical approach to better understand the school experiences of autistic students and to provoke change in the day-to-day practices of teachers and operations of schools.

**Combining Critical Disability Theory with a Phenomenological Researcher Lens in Autism Research**

**Critical Disability Theory**

Critical disability theory emerged from the disability rights movement in the 1970s (Meekosha & Shuttleworth, 2009). Over the decades, critical disability theory has evolved from a social critique of disability to an inter/trans-sectionalist interpretation that examinees disability from interconnected viewpoints, including postcolonial, political, queer, and feminist theories (Goodley, 2013). The inter/trans-sectionalist elements of critical disability theory allow researchers to consider how “conditions of dominance crisscross in ways that promote values and, simultaneously, justify forms of oppression such as disablism, racism, homophobia and orientalism that negate the existence of Others” (Goodley, 2013, p. 637). Modern disability theorist, Goodley (2013) views critical disability theory as a “location” (p.974), where inquiry may “start with disability but it never ends with it: disability is the space from which to think through a host of political, theoretical and practical issues that are relevant to all” (p.632). One of the valuable aspects of intersectionality within critical disability theory is that it has improved outdated views that have historically equated disability with impairment. Where more recently disability is considered a problem of society (Goodley, 2013), impairments are “object(s) independent of knowledge” (Shakespeare, 2006, p.54); they are elements of a person’s biology that affects people’s lived experiences in static, episodic, degenerative, and terminal ways (Goodley, 2013).
**Phenomenological Research Lens**

Contemporary phenomenological research draws on the work of Edmund Husserl’s (1859-1938) transcendental phenomenology and Martin Heidegger’s (1889-1976) hermeneutic phenomenology (Eddles-Hirch, 2015). Where transcendental phenomenology delves deep into the consciousness of the experiencer to unveil underlying structures of the phenomenon, hermeneutic phenomenology takes an interpretive approach to study the lifeworld of the experiencer (Eddles-Hirch, 2015). Researchers use phenomenology as both a theoretical framework and a research method (Eddles-Hirch, 2015). This study’s application of phenomenology is to integrate elements of its theoretical and methodological strengths. This approach allows me to design an ethically robust study that centers on a critical disability framework and autistic experience. Additionally, because each theoretical framework has its own unique biases, one framework’s strengths can be used to address the other’s limitations. For example, phenomenology has been critiqued by critical theorists for its over-reliance on “medicalised and individualised understandings of disability” (Paterson & Hughes, 2010, p. 597), and critical disability theory has been criticized by feminists and cultural studies scholars for its binary (medical-social) views of disability and impairment (Meekosha & Shuttleworth, 2009). Thus, to confront tenets of ableism found in phenomenology (Paterson & Hughes, 1999), critical disability theory is useful because it re-connects the disabled body back into the consciousness of the experiencer (Goodley, 2013). Phenomenology helps confront binary views of disability found in critical disability theory by seeking to understand the essence of the experience of disability and impairment and how people make sense of these experiences in their everyday world (Eddles-Hirch, 2015).
It is interesting to note the political histories Heidegger and Asperger share, namely, their affiliation with the Nazi Party (Petzet, 1993). I draw attention to this fact because it serves as a reminder for us to consider the implications of the epistemological underpinnings of the theoretical frameworks we use and the ensuing effects on knowledge production and the ways we treat people. Charmaz (2012) argues that “standpoints and starting points matter” (p.14) and Denzin (2008) defends that interpretation of data is inherently political. Essentially our epistemological positions, which are guided by our personal histories, life experiences, and motivations shape both how we do research and what we see (Charmaz, 2012).

**Autism Research**

Research on the theoretical and methodological approaches used to study the lived experiences of autistic people suggests that phenomenology is advantageous because it “treats participants as experts” (Howard et al., 2019, p.1) and examines knowledge and understanding from first-hand accounts (Lawlor & Solomon, 2017). In a study titled “A systematic literature review on the qualitative methods used for eliciting the views of young people with ASD on their educational experiences” (2017), authors Fayette and Bond (2017) defend that a majority of qualitative studies were unable to elicit the diverse views and experiences of autistic youth because of low methodological quality. However, Fayette and Bond (2017) uphold phenomenology as an appropriate approach to study autistic people’s subjective experiences because of its “commitment to equality of voice and researcher reflexivity” (p.1). Howard et al. (2019) also argue that a benefit of using phenomenology in autism research is that through researcher reflexivity, researchers can “consider the impact (both positive and negative) of their own experiences and preconceptions on research design and procedures” (p.1). Another positive quality of phenomenology is that it values researcher knowledge and experience, which is
advantageous because it helped to inform the study design and to guide my interpretations of autistic students’ school experiences (Gadamer, 1976). Specifically, I was able to leverage my knowledge and experiences on the benefits of using technology with autistic students to design an online survey that increased accessibility and improved the authentic engagement of autistic participants.

Commensurable with phenomenology’s commitment to researcher reflexivity and equality of voice, critical disability theory is “self-critical and reflexive” (Goodley et al., 2019, p.976) and seeks to reimagine concepts of ability and disability by valuing diversity in lived experiences based on a person’s unique mind-body interactions. Notably, combining a phenomenological research lens with critical disability theory is novel and requires a type of conceptual “radicalization” (Paterson & Hughes, 1999, p.597). This radicalization involves compelling the researcher and those of us in positions of power to re-construct knowledge based on the views and experiences of differently-abled people.

Thus, combining a critical disability theoretical framework with a phenomenologically informed research lens to explore the self-reported school experiences of autistic students is advantageous for the following reasons:

a) Acknowledging the strengths and weaknesses of each approach increases the fidelity of the study, including the ethical provision of time and space for autistic students to authentically share their identity, voice, and interpretations of their experiences.

b) Including inter/trans-sectionalist perspectives from disability, political, postcolonial, and feminist theories promotes unity amongst marginalized people
while offering opportunity to recognize and respond to forms of oppression within and between marginalized groups.

c) Researcher bias and ableist practices are minimized by engaging in evaluation and self-reflection in each stage of the research process; and
d) Power differentials between researcher and participant are addressed openly, thus can more likely be minimized throughout the research process.

**Online Methods and Autism Research.** Autistic space is frequently referred to as another world, and many therapies and interventions have aimed to coax autistic individuals from their world into the real world (Sinclair, 2010). Through self-accounts from speaking and non-speaking autistics, we are challenged to reconsider the perception of autistic space as inferior space. Sinclair (2010), an autistic self-advocate, defends that there are three types of spaces that he lives in—neuro-typical space, one’s own space, and shared autistic space. Sinclair describes the challenges of living inauthentically in neuro-typical space:

> Being autistic among non-autistic people is likely to consist of not understanding what other people are doing or why they are doing it, or what they expect us to do; not being understood when we ask questions or try to join in, being misunderstood in hurtful ways…being subjected to noxious stimuli as the price of social participation; and being expected to maintain a level and pace of participation that is overwhelming and draining for us (para. 17).

Conversely, Sinclair (2010) defends that “being in ’one’s own space’ means having control over the space itself, over what one does in the space, and over who has access to that space” (para. 19).
Similarly, researchers experienced in conducting studies to elicit the voices of autistic people uphold the benefits of online methods because computer-mediated communication breaks down physical, geographical, and attitudinal barriers and eliminates social environments that impede authentic communication during face-to-face interviews (Benford & Standen, 2011; Heiskanen & Egerer, 2019; Ison, 2009; Scott-Barrett et al., 2019). Furthermore, online environments are considered a beneficial way to reduce power differentials and strengthen rapport because autistic participants have more control over the research setting and engagement in the research process (Benford & Standen, 2011; Scott-Barrett et al, 2019). Online participation also provides an additional level of anonymity versus face-to-face or telephone interviews, which may encourage autistic participants to “be themselves” (Benford & Standen, 2011, p. 356) when sharing their views and experiences, especially relating to personally sensitive topics (McCoyd & Kearson, 2006). Research also shows that email is a preferred means of communication amongst autistic people, more than face-to-face communication, even when interacting with friends (Benford & Standen, 2011; Ison, 2009). Reasons for autistic students’ preference for email communication is that computer-mediated communication reduces “social, emotional and time pressures of interpersonal communication” (Benford & Standen, 2011, p.364) and provides more opportunity for autistic students to be viewed as equals rather than for their autistic stereotypes (Scott-Berrett et al., 2019).

*Ethical Spaces in Education and Research*

Ethical spaces disrupt power imbalances and provide growth opportunities when tension exists between people and ideas (De Schauwer et al., 2018). Creating ethical spaces in research is an epistemological and moral imperative (Ahmed, 2002; Chown et al., 2017) because too often, researchers draw boundaries around people and their experiences (Cariou, 2014). While
qualitative educational research has been criticized for being slow in its use of online research methods (James, 2016), online spaces provide opportunities for autistic students to construct their narratives while minimizing the effects of “time-space compression” (p.154). Time-space compression is viewed by disability theorists to be filled with power, control, and inequality because autistic people are expected to perform according to non-autistic communicative standards (James, 2016). Bowker and Tuffin (2004) suggest that creating ethical spaces in research, specifically through email, empowers participants because they have control over how, when, and where they participate, thus ensuring the relationship between research and participant is more democratic (James, 2016).

Ethical spaces offer opportunities for ethical listening, which works to minimize the objectification of the speaker and subject through “dividing practices” (Foucault, 1982, p. 777). Listening to the ideas and experiences of autistic people requires that researchers attend to and value multiple forms of communication, including uncustomary sounds, symbols, gestures, rhythms, and repetitions. Stuart Murray, researcher and parent of a non-speaking autistic child, stated, “Autism is frequently talked about, but it is rarely listened to” (p. XIII). In the absence of ethical listening, researchers and educators potentially misrecognize or conversely, fail to recognize (Couthard, 2014) the experiences and personhood of autism.

Consequently, these mistakes in recognition lead to feelings of exclusion, self-doubt, loneliness, and depression (Rosa & Mountian, 2013). When neuro typical developing children feel recognized by teachers, they report an increased sense of wellbeing, including a positive sense of self, security, and agency (Foley et al., 2011). Unlike their peers, and despite being characterized by social-communication impairments, autistic students also benefit from being listened to, including increased rates of school participation, academic success, and overall
school satisfaction (Saggers et al., 2011; Saggers, 2015). Teachers who create ethical classroom spaces, and model ethical listening practices, create safe opportunities for students to express themselves and celebrate diversity in their peers. Unsurprisingly, teachers who engage in ethical listening are more knowledgeable about their students’ strengths and needs and can effectively identify and use adequate supports and strategies (Saggers, 2015; Woodfield & Ashby, 2016).

**Research Design Overview**

Student perception data was gathered through a mixed-method convergent parallel research design. Mixed-method convergent parallel means that quantitative and qualitative data were collected in a similar timeframe, analyzed separately, and then merged for more in-depth analysis (Fetters et al., 2013). The benefits of using a mixed-method design are the strengths of one method help to overcome the weaknesses of the other, the validity of the data is increased through triangulation, and through data integration, strong evidence is available to draw conclusions (Greene et al., 1989; Mayoh & Onwuegbuzie, 2015). Methods used to collect quantitative and qualitative data align with critical disability theory in that flexible opportunities for participants to self-select their preferred time and mode of engagement were supported through asynchronous (online survey) and synchronous (email interview) platforms (Friesen et al., 2019). Quantitative survey data \((n=72)\) were analyzed using descriptive statistics, and qualitative data (open-ended survey response \(n=19\) and email interview \(n=10\)) were analyzed using inductive thematic analysis. Quantitative and qualitative data were given equal priority (QUAN+QUAL) and upon completing separate initial analyses, quantitative and qualitative findings were merged using a joint display technique called the Pillar Integration Process (PIP) (Johnson et al., 2019). The PIP provided a rigorous four-stage method to integrate QUAN and QUAL findings to generate wholistic insights into the school experiences of autistic students and
to clearly identify instances of discrepancy or variance in students’ experiences (Johnson et al., 2019).

**Recruitment, Research Setting, Participants and Data Sources**

**Recruitment**

People with disabilities are often overlooked in research because flexible recruitment strategies and accommodations are not provided (Aldridge, 2007) and tensions between protection from harm and the right for autonomy (McDonald et al., 2013). Research shows that disabled participants prefer to enlist the support from familiar people “to help them assess the value or appropriateness of participation” (McDonald et al., 2013, p. 220) and accessing support helps to increase their contribution to the research (McDonald et al., 2013). Upon receiving ethics approval from the University of Calgary’s Conjoint Faculties Research Ethics Board (CFREB), the first recruitment phase began. A convenience sampling method was used (Steward et al., 2018), specifically, snowball sampling (Lewis-Beck et al., 2004; Kenny et al., 2016) by sending an email (see Appendix E) to publicly available contacts at provincial and territory autism stakeholder groups (Autism Manchester, 2017; Baltar & Brunet, 2012; Cage et al., 2018). Three attachments were included in the introductory email: first, a parent information letter (see Appendix F); second, a Student Information Booklet (see Appendix G) that provided an in-depth summary of the research, including information related to the purpose of the study, benefits, and risks of participation, eligibility requirements, consent process, details of the online survey and email interview, and contact information; and third, a social media image of the research invite was also included if the agency decided to share the research invite. All recruitment emails were logged in a tracking form, which included the agency, superintendent or parent council’s contact name, the date email was sent, and the date and type of response received.
Careful consideration was also given to the individual needs of participants who completed the email interview. Interview times were accommodated to support participant schedules, including personal work schedules and time zones. Additionally, the wording used in email correspondence and during the interview was stated clearly and positively to build trust and convey researcher enthusiasm. Re-assuring phrases such as “to the best of your ability”, “take as much time as you need”, and “you are welcome to take a break” were also used. A form of online listening helped to monitor “conversational tone” (Benford & Standen, 2011, p. 362), including participant stress, disinterest, and misunderstanding, and to maintain a safe and positive online space for participants. For example, at the start of an interview a participant shared before answering the first question “Just want to let you know that I am starting to answer the questions. I will get back to you as soon as I can” and immediately after providing his response, he stated “Sorry I am a slow typer. If you have more questions don’t worry about the time and I will get back to you”. Which conveyed to me that the participant was concerned about my perception of his engagement in the research because he perceived himself to be a “slow” typer. Therefore, in attempt to minimize pressure on the participant to respond quickly, I used reassuring phrases throughout the interview and avoided using compound questions. All email participants were thanked and commended for their responses, and following notification of the end of the interview, participants received an e-gift card to thank them for their time and participation.

Revisions to Recruitment Procedures

Due to continued lower than anticipated response rates, two revisions to this study were approved by CFREB. The first revision was made to include school superintendents and parent councils in snowball sampling methods, which resulted in one superintendent of a private school
sharing the research invite to students following school-board ethical approval. The second revision occurred to use convenience sampling (Berinsky et al., 2012) through Amazon’s Mechanical Turk (MTurk). Although not frequently used in autism research, MTurk is a reliable crowdsource platform to access research subjects. MTurk has been used in research since 2005 (Buhrmester et al., 2011) and has been described as an effective method to recruit hard-to-reach populations, including those with disabilities (Anderson et al. 2019; Smith et al., 2015). The MTurk posting closed within 24 hours because the maximum of 50 survey completes was reached, with two additional surveys completed after access via MTurk was closed. Participants from MTurk received two dollars for completing the online survey and a twenty-five-dollar Amazon e-Gift card for participating in the 30-minute email interview. This additional compensation was deemed fair and reasonable by CFREB and successfully increased participant interest in the research, which was an identified issue in Phase 1 and Phase 2 of the research. Recruitment for quantitative data collection ended once 70 surveys were completed, and recruitment for qualitative data collection ended once ten semi-structured interviews were completed. The total number of participants for both the survey \((n=72)\) and email interview \((n=10)\) were slightly higher than targets identified in the research proposal, which initially identified 65 participants to complete the online survey and five to seven participants to complete the semi-structured email interview. The minimum number of participants required to complete the survey was determined by estimating that five participants from each province and territory would complete the survey. The target number of participants was informed by comparative studies presented in the literature review and my own research experiences, specifically working with the *Worktopia: School Works Canada* research project (Worktopia, 2020). The decision to
end quantitative and qualitative data collection was informed by recruitment targets met after 12 weeks of recruitment and an expended budget for participant compensation.

**Research Setting**

Participants responded to the online survey and email interview questions from their “own space” (Sinclair, 2010, para.9), which included their home or familiar and comfortable community setting where they had access to a computer, smartphone or tablet and the internet. As previously stated, providing an opportunity for participants to share their experiences from their own space is empowering because it allows for autistic participants to “gain visibility and invisibility at the same time-claiming a voice without having to claim a body” (Parsloe, 2015, p.340). Additionally, participant access to individually owned spaces supports self-determination regarding when and how long participants will engage in the research (Tavassoli et al., 2014).

Having participants respond from institutional settings including schools, was discouraged as to avoid any associations related to confidentiality, power, control, assessment, and appropriate answers and behaviour (Holloway & Valentine, 2000). Also worth noting, students could independently access familiar supports if required (Nicolaidis et al., 2013). Supports may have included a family member, support worker or friend who assisted with physical navigation, reading the questions aloud or completing online scribing of participant responses. Therefore, the selection of asynchronous and synchronous methods used in this study aligns with critical disability theory on how to elicit first-hand accounts from disabled participants because the methods are responsive to the self-identified preferences for social and communicative engagement of autistic people.
Methodology

Participants

Eligible participants were Canadian citizens between the ages of 15 and 21 years old and completed a minimum of one year of high school in Canada. Participants who completed the online survey via Amazon’s Mechanical Turk also met eligibility conditions based on the demographic information they entered when registering for their Amazon MTurk accounts. Participants self-reported having a diagnosis of Autism Spectrum Condition (ASC), Asperger’s Syndrome (AS) or Pervasive Developmental Disorder-Not Otherwise Stated (PDD-NOS). Participants self-identified as speaking, non-or minimally speaking, or comfortable using non-speaking modes of communication to participate in the research. Participants required access to technology, including a smartphone, tablet or a computer, and the internet to participate in the survey and the email interview.

Demographic Summary of Survey Participation. This study comprised of three phases of data collection. In Phase 1, 108 emails were sent to various provincial and territory autism agencies, and self-advocacy groups. In Phase 2, 155 emails were sent to provincial and territory autism agencies, self-advocacy groups, and superintendents of schools. In Phase 3 one posting was made on Amazon’s MTurk. After three phases of data collection a total of 70 surveys were completed in full and one survey was 63% completed, and another survey 46% completed. Thus, 72 surveys were included in quantitative data analysis. Three surveys were removed from count because one respondent completed the survey twice, and Qualtrics identified two surveys as spam. Overall, most participants resided in Ontario (n=23/72 or 32%), British Columbia (n=20/72 or 28%), and Alberta (n=15/72 or 21%). Slightly more than half of the participants completed grade 10 (n=40/72 or 56%) and most identified with ASC (n=53/72 or 74%). Slightly over half of the participants identified as male (n=40/72 or 56%), 36% (n=26/72) identified as
female, and 5% identified as non-binary ($n=3/72$) or queer ($n=1/72$). The larger representation of males is likely attributed to diagnostic gender bias, where three males for every one female receives an autism diagnosis (Loomes et al., 2017). Slightly more than half of the participants ($n=41/72$ or 57%) preferred non-speaking modes of communication such as typing ($n=37/72$ or 51%) or other ($n=4/73$ or 5%), which included drawing and art. Most students indicated that they were motivated to participate in the research because of a chance to win a gift card ($n=34/72$ or 47%), and nearly a quarter of participants ($n=17/72$ or 24%) received support to complete the survey. Table 1 provides a summary of participant demographics for the online survey.

**Table 1**

**Summary of Participant Demographics for the Online Survey**

<table>
<thead>
<tr>
<th>Recruitment and Impact</th>
<th>Target Community</th>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Autism Agencies and Self-advocacy Groups</td>
<td>School Superintendents and Parent Councils</td>
<td>Amazon’s Mechanical Turk</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emails Sent</td>
<td>108</td>
<td>155</td>
<td>1 posting</td>
<td>264</td>
<td></td>
<td>n/a</td>
</tr>
<tr>
<td>Survey’s Completed</td>
<td>12</td>
<td>8</td>
<td>52</td>
<td>72</td>
<td></td>
<td>n/a</td>
</tr>
<tr>
<td>Location of Participants</td>
<td>BC, AB, ONT</td>
<td>BC, AB, ONT, NFLD, YKT</td>
<td>BC, AB, SK, MB, ONT, QC, NFLD, NS, NWT, YKT</td>
<td>8 provinces 2 territories</td>
<td></td>
<td>n/a</td>
</tr>
<tr>
<td>Grade Completed</td>
<td>Gr. 12</td>
<td>2</td>
<td>3</td>
<td>10</td>
<td>15</td>
<td>21%</td>
</tr>
<tr>
<td></td>
<td>Gr. 11</td>
<td>3</td>
<td>3</td>
<td>11</td>
<td>17</td>
<td>24%</td>
</tr>
<tr>
<td></td>
<td>Gr. 10</td>
<td>7</td>
<td>2</td>
<td>31</td>
<td>40</td>
<td>56%</td>
</tr>
<tr>
<td>Diagnostic Identity</td>
<td>Autism Spectrum Condition (ASC)</td>
<td>12</td>
<td>4</td>
<td>37</td>
<td>53</td>
<td>74%</td>
</tr>
<tr>
<td></td>
<td>Asperger’s Syndrome (AS)</td>
<td>3</td>
<td>3</td>
<td>9</td>
<td>15</td>
<td>21%</td>
</tr>
<tr>
<td></td>
<td>Pervasive Developmental Disorder (PDD)</td>
<td>1</td>
<td>1</td>
<td>6</td>
<td>8</td>
<td>11%</td>
</tr>
<tr>
<td>Gender Identity</td>
<td>Female</td>
<td>3</td>
<td>2</td>
<td>21</td>
<td>26</td>
<td>36%</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>7</td>
<td>3</td>
<td>30</td>
<td>40</td>
<td>56%</td>
</tr>
<tr>
<td></td>
<td>Gender Queer</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td></td>
<td>Gender Non-binary</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>4%</td>
</tr>
<tr>
<td>Comm. Preference</td>
<td>Speaking</td>
<td>7</td>
<td>4</td>
<td>20</td>
<td>31</td>
<td>43%</td>
</tr>
<tr>
<td></td>
<td>Typing</td>
<td>3</td>
<td>2</td>
<td>32</td>
<td>37</td>
<td>51%</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>4</td>
<td>5%</td>
</tr>
<tr>
<td>Reason for Participating</td>
<td>Gift Card</td>
<td>12</td>
<td>2</td>
<td>20</td>
<td>34</td>
<td>47%</td>
</tr>
<tr>
<td></td>
<td>Incl. speaking/ non-speaking</td>
<td>7</td>
<td>3</td>
<td>16</td>
<td>26</td>
<td>36%</td>
</tr>
<tr>
<td></td>
<td>Share experiences</td>
<td>2</td>
<td>4</td>
<td>20</td>
<td>26</td>
<td>36%</td>
</tr>
<tr>
<td>Support Received</td>
<td>Yes</td>
<td>5</td>
<td>2</td>
<td>10</td>
<td>17</td>
<td>24%</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>7</td>
<td>6</td>
<td>42</td>
<td>55</td>
<td>77%</td>
</tr>
</tbody>
</table>

*Note: Terms cisgender male and cisgender female would have been more appropriate terms to use in the Gender Identity section of the survey.*
Demographic Summary of Email Interview Participants. Of the 10 participants who completed the interview, three participants shared that they preferred to speak to communicate, six participants shared that they preferred to type to communicate, and one participant shared that they preferred to draw to communicate. Only participants (n=6) who identified typing or another non-speaking mode of communication (n=1), as their preferred mode of communication, were asked to expand on their preferences for using non-speaking communication. Participants from the email interview were randomly assigned pseudonyms at the start of data analysis. Assigned pseudonyms were not approved by participants and may not reflect their cultural or gender identity. Table 2 provides a summary of participant demographics for the email interview.

Table 2

Summary of Participant Demographics for the Email Interview

<table>
<thead>
<tr>
<th>Location of the Participant</th>
<th>Charlie</th>
<th>Armani</th>
<th>Kai</th>
<th>Azariah</th>
<th>Frankie</th>
<th>Sam</th>
<th>Taylor</th>
<th>Alex</th>
<th>Zia</th>
<th>Lennon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade Completed</td>
<td>BC</td>
<td>BC</td>
<td>ONT</td>
<td>ONT</td>
<td>BC</td>
<td>BC</td>
<td>AB</td>
<td>BC</td>
<td>BC</td>
<td>BC</td>
</tr>
<tr>
<td>Diagnostic Identity</td>
<td>ASC</td>
<td>ASC</td>
<td>AS</td>
<td>ASC</td>
<td>ASC</td>
<td>ASC</td>
<td>ASC</td>
<td>ASC</td>
<td>ASC</td>
<td>ASC</td>
</tr>
<tr>
<td>Communication Preference</td>
<td>Speaking</td>
<td>Speaking</td>
<td>Speaking</td>
<td>Typing</td>
<td>Typing</td>
<td>Typing</td>
<td>Typing</td>
<td>Typing</td>
<td>Typing</td>
<td>Other</td>
</tr>
</tbody>
</table>

Data Sources

Four primary sources informed the selection of the quantitative data collection instrument and qualitative interview questions: 1) The Panorama Survey (Gehlbach, 2014); 2) The Person-Oriented Autism Research Ethics (Cascio et al., 2019) task force recommendations on how to design ethical studies that are responsive to the strengths and needs of autistic people; 3) Research by Nicolaidis’(2013; 2015) that highlights best practices to adapt instruments to be more accessible to autistic individuals; and 4) Literature on student perception surveys including
publications, “Student perception surveys for K-12 teacher evaluation in the United States: A survey of surveys (Geiger & Amrein-Beardsley, 2019) and “Instruments for obtaining student feedback: A review of the literature” (Richardson, 2005). Together these sources helped to support the authentic participation of autistic students and ensure that perception data relating to social, emotional, sensory, and learning experiences originated from student reflections opposed to teacher and parent observations.

Data Collection

Quantitative Data Collection: The Panorama Survey

The Panorama Survey (Gehlbach, 2014) is a free and open-source survey developed by a research team from the Harvard Graduate School of Education (Geiger & Amrein-Beardsley, 2019). The Panorama Survey (Gehlbach, 2014) consists of two main categories of scales, the first category relates to classroom and teaching, and the second category relates to the school in general. Each category consists of 10 scales that school organizations can select from, depending on their needs and context. The ten scales are classroom climate, engagement, grit, learning strategies, mindset, pedagogical effectiveness, rigorous expectations, school belonging, teacher-student relationships, and valuing of the school. The Panorama Survey (Gehlbach, 2014) was selected for three main reasons: 1) Its robust design to gather student perception data on their educational experiences; 2) Its explicitly stated customizable features; and 3) The authors of the survey are experts in education and have extensive experience in developing scales in education (Geiger & Amrein-Beardsley, 2019). The Likert style questions apply to students from various socio-economic backgrounds, in grades 6-12 who attend public, independent or charter schools.

To minimize error and to build construct validity, the Panorama Survey (Gehlbach, 2014) was developed through a six-step design process including 1) Literature review; 2) Interviews
and focus groups; 3) Synthesis of indicators; 4) Item creation; 5) Expert review; and 6) Cognitive pre-testing and interviewing (Gehlbach & Brinkworth, 2011). The authors of the Panorama Survey (Gehlbach, 2014) used a rigorous testing approach (i.e. two large scale pilot studies) to ensure their instrument and scales measure the psychological attributes they are intended to measure (i.e. their psychometric properties 19-module instrument). Reliability ensures that the survey item consistently draws the same response from students in similar conditions and differences can be attributed to different student perceptions of their experiences. Structural validity examines if the items in each scale measure one or multiple underlying factors. Each of the ten survey scales have strong coefficient alpha, with each scale being 0.70 or greater and sound structural validity established through confirmatory factor analysis (Panorama Education, 2015). Finally, in both pilot tests, different forms of the survey were presented to random samples of students to test phraseology and comparisons to other well-known scales. Test results indicated strong discriminant and convergent validity (Gehlbach, 2014; Panorama Education, 2015). However, similar to other student perception surveys, peer-reviewed research on the Panorama Survey (Gehlbach, 2014) is minimal (Geiger & Amrein-Beardsley, 2019).

For the purposes of this study, 18 survey items were selected from eight survey scales and were chosen based on their likeliness to gather student perception data from autistic students to answer the research question. Cronbach’s alpha was used to test scale reliability. A value of 0.7 to 0.95 is considered acceptable (Tavakol & Dennick, 2011). Chronbach’s alpha test in SPSS was used to identify the reliability of survey items. The survey items have relatively high internal consistence because the calculated alpha coefficient of the 18 survey items is 0.825. A summary of the 18 survey items is provided in Table 3.
### Table 3

**Summary of Survey Items**

<table>
<thead>
<tr>
<th>Description</th>
<th>Survey Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Student perceptions of the quality of teaching and learning.</td>
<td>1. How often do you receive feedback at school?</td>
</tr>
<tr>
<td>How much students feel that school is interesting, important, and useful.</td>
<td>2. How comfortable are you asking questions about what you are learning?</td>
</tr>
<tr>
<td>How attentive and invested students are in school.</td>
<td>3. How interesting is school?</td>
</tr>
<tr>
<td>How much students feel that their teachers hold them to high expectations around effort, understanding, persistence, and performance in class.</td>
<td>4. How excited are you to go to school?</td>
</tr>
<tr>
<td>How strong the social connection is between teachers and students within and beyond school.</td>
<td>5. How eager are you to participate in your classes?</td>
</tr>
<tr>
<td>How much students feel that they are valued members of the school community.</td>
<td>6. How often do your teachers take the time to ensure you understand the material?</td>
</tr>
<tr>
<td>Perceptions of student physical and psychological safety while at school?</td>
<td>7. How much do your teachers encourage you to do your best?</td>
</tr>
<tr>
<td>Perceptions of the overall social and learning climate of the school.</td>
<td>8. Overall, how high are your teachers’ expectations of you?</td>
</tr>
<tr>
<td></td>
<td>9. How many of your teachers are respectful towards you?</td>
</tr>
<tr>
<td></td>
<td>10. How many of your teachers would you be excited to see again in the future?</td>
</tr>
<tr>
<td></td>
<td>11. Overall, how much do you feel like you belong at your school?</td>
</tr>
<tr>
<td></td>
<td>12. How well do peers at your school understand you as a person?</td>
</tr>
<tr>
<td></td>
<td>13. How much respect do your peers in your school show you?</td>
</tr>
<tr>
<td></td>
<td>14. How often do you worry about bullying at school?</td>
</tr>
<tr>
<td></td>
<td>15. How often do you worry about online bullying?</td>
</tr>
<tr>
<td></td>
<td>16. How fair or unfair are the rules at school?</td>
</tr>
<tr>
<td></td>
<td>17. How pleasant or unpleasant is the physical space at your school?</td>
</tr>
<tr>
<td></td>
<td>18. How positive or negative is the energy at school?</td>
</tr>
</tbody>
</table>

To increase accessibility to the survey questions and to support the authentic engagement of autistic participants, the following survey accommodations were made (see Appendix C):

a) Adaption from a paper format to an online format, thus aligning with research that shows autistic individuals prefer electronic communication over other forms (Kourti & MacLeod, 2019; Scott-Bennett et al., 2019).

b) Vocabulary on five of the survey items was slightly modified to ensure that questions were contextually meaningful, concise, and concrete (Nicolaidis et al., 2013; Kenny et al., 2016). For example, the original question “How excited are you to go to this class?” was changed to “How excited are you to go to this school?”.

c) Survey items were presented in a low-stimulating visual format supported by visual cues (Scott-Bennett et al., 2019); and
Methodology

d) Invitations for participants to access familiar supports to participate in the research and reduce potential feelings of stress were included (Nicolaidis et al., 2013).

**Qualtrics.** Quantitative survey data were collected using Qualtrics, an online survey program made accessible by the University of Calgary. The highly customizable features of Qualtrics allowed for the design of a user-intuitive, visually engaging, and textually minimal survey. Each survey question was displayed on a separate page with an image to assist with comprehension and improve interest. At the bottom of each page was a survey completion bar to inform participants of their progress. Study information and consent forms were available online and for download at the beginning of the survey. Participants who completed the survey could also voluntarily provide an email address to enter a draw to win an online $50 Amazon e-gift card. Qualtrics recorded the average completion time by participants as approximately nine minutes. All survey responses are stored, and password protected in Qualtrics for five years.

**Qualitative Open-Ended Survey Responses**

One open-ended question was included at the end of the survey to invite participants to share additional information on their school experiences that may not have been collected through survey items. A total of 19 participants completed the open-ended survey question, and one of the 19 participants also completed the semi-structured email interview. Overall, students’ open-ended responses provided personal opinions on liking or not liking school, such as “yes My School Life is Wonderful Enjoying Very Much” or “School was a horrible experience. IT was not until i was 18 that they discovered i was autistic.” Most open-ended responses averaged 32 words or two sentences in length and the most extended response was 176 typed words. All open-ended survey responses are included in the qualitative data analysis and are password protected within Qualtrics for five years.
**Qualitative Semi-Structured Email Questions**

After completing the online survey, participants were invited to be part of a synchronous 30-minute semi-structured email interview. Participants consented to participation by voluntarily providing their email address within Qualtrics. Once participants provided their email addresses, they were contacted by me via email to review the semi-structured email interview format and to set up a mutually convenient time to complete the interview. Based on the first interviewee’s response, I learned that beginning the interview with an open-ended question may have been too ambiguous and perhaps inadvertently placed pressure on the participant to lead the interview. For example, in response to the following opening question:

> First, is there anything that stands out for you that you would like to share about your school experiences that were not captured by completing the survey? This email interview is flexible, so we can talk about whatever may be important to you or I can start with a couple of questions based on the survey.

The participant replied, “I am not really sure. I’ve had a lot of school experiences so nothing jumps out at me immediately. Do you have any topic suggestions or questions?”. Thus, in response to participant feedback, the semi-structured email format was adapted to enhance student engagement. This adjustment is an example of how researcher reflexivity was used to guide the succeeding structure and style of the semi-structured email interview. Bryman and Cassell (2006) describe this type of researcher response as cultivated reflexivity. Researchers make responsive decisions to make interviews more meaningful to participants, which requires researchers to be both an observer and a participant during the interview process (Scott-Barrett et al., 2019). Henceforth, each subsequent interview began with a question based on a survey item along with an openness towards student led topics. For example, when a participant shared that
he liked the gymnasium’s openness, I followed by asking him about the type of activities he liked to do in the gym. Also, when required, interview questions were altered to support students’ comprehension of the question. For instance, when asked a question about peers, a participant replied, “could u ask me the same question again but with using different words. I can't really get the question”. To ensure ongoing assent, participants were informed of the time left in the interview and were asked if they wanted to continue the interview. Additionally, I would provide encouraging statements at the beginning, and throughout the interview, such as “Please don't feel rushed, take as much time as you need to respond”; and to conclude the semi-structured email interview, I would make a statement such as “Thank-you Zia, your answers are really informative, and I appreciate you sharing with me. I want to be respectful of your time, so I will end the interview here unless you would like to share more?”.

Semi-structured interview questions were based on survey items (see Appendix D). Participant’s survey responses were not reviewed before conducting the interview. However, participants’ communication preferences identified in the survey’s demographic portion were reviewed before conducting the semi-structured interview. The reason for reviewing a participant’s preferred mode of communication before the email interview was to ensure that researcher questions and the ensuing discussion were not structurally presumptive towards speaking communication and to provide an opportunity for participants to expand on their communicative preference, should they wish. Based on survey items, four main questions provided a flexible framework to guide the semi-structured email interview. These questions were selected based on significant themes identified in the literature review combined with my professional knowledge and experience working with autistic students. In most instances, not all the same questions were posed to participants. Instead, topics of discussion raised organically by
participants were followed. The four main questions that were used to initiate and guide the interview are:

1. What school spaces are the most calming for you?
2. Describe a time where you felt respected by a peer?
3. In your opinion, what are the characteristics of a great teacher?
4. Can you tell me more about your preference for non-speaking communication?

Since the interview was conducted via email, which included markers of dates and times, no additional transcription was required. While the average time to complete the interview was 35 minutes, the most extended interview took two hours, where the participant apologized for being a “slow typer” and stated, “if you have more questions, don't worry about the time and I will get back to you”. The average word length of email interview responses was 331 words. The minimum number of typed words was 222, from a participant who indicated that their preferred mode of communication was typing, and their interview time totalled two hours. The maximum number of typed words was 459, from a participant who indicated that their preferred mode of communication was speaking, and their interview time totalled 30 minutes.

The difference in typed words between the participant who stated they preferred to type to communicate (typed 222 words in two hours) versus the participant who indicated they preferred to speak to communicate (typed 459 words in 30 minutes) highlights the diversity in autistic presentation and ability in relation to ableist concepts of time, and should serve as a reminder to researchers to avoid making assumptions and generalizations on autistic ability based on time and communication preferences. Additionally, the length of typed responses might be viewed as small and insufficient by some researchers; however, the length of students’ email responses does not reflect the quality or validity of data (Heiskanen & Egerer, 2019). Participants received
a $25 Amazon e-gift card immediately following the interview. All email transcripts are password protected and encrypted in a digital file that is accessible only to me and will be destroyed after five years.

The advantages of providing two separate opportunities (open ended survey question and email interview) for autistic participants to share their personal perspectives on their school experience are:

a) Students interested in completing only the survey portion of the research could provide additional information in the open-ended survey question; and

b) Students interested in sharing in-depth experiences via virtual social engagement could volunteer to participate in the email interview and receive compensation.

Importantly, the separation of quantitative and qualitative data collection supported participant decision making during the consent process (Bampton & Cowton, 2002), where participants learned that the survey would take approximately 10-15 minutes to complete, and the interview would take approximately 30-minutes to complete. Providing participants with a schedule of time obligations prior to engaging in the research is known to build trust and rapport between the participant and the researcher and reduces participant abandonment, respondent fatigue, frustration related to comprehending questions, and inequitable compensation (Benford & Standen, 2011; Scott-Barrett et al, 2019). Thus, providing participants with two separate opportunities to participate in the research highlights the inclusive design and methodological integrity of the research because it increases accessibility, respects individualization, and supports autistic students’ autonomy in decision making.
Methodology

**Procedures for Data Analysis**

The mixed-method convergent parallel design of the study meant that while quantitative and qualitative data were collected concurrently in a single phase, data sets from the survey responses and semi-structured interviews were analyzed separately and then integrated for final analysis. To maintain the centrality of autistic student voice in my interpretations of their school experiences, qualitative sub-themes were not transformed into quantitative categories to facilitate the integration of mixed-method data collection. This decision helped to protect the authenticity of student voice and ensured that the quantitative component of this mixed-method study did not dominate (Charmaz, 2012).

**Integration of Quantitative Data and Qualitative Data**

The integration of quantitative and qualitative data is beneficial because it generates new insights that may not be discoverable in separate presentations of data, and it is a way to illuminate unique findings (Bazeley, 2009). For example, the survey question related to participants’ preferred mode of communication was interesting because more than half (56%) of autistic students shared that they preferred to use non-speaking modes of communication. Subsequently, this learning prompted me to explore the phenomenon more deeply in the semi-structured interview, resulting in a more profound understanding and awareness of why and under what conditions autistic students prefer to use non-speaking modes of communication. Which notably may not have occurred if I only used one single data source to gather student perception data. Thus, the integration of quantitative and qualitative data occurred in two stages. The first stage of data integration occurred through methods, where survey questions informed the semi-structured email interview questions, and the second stage of data integration occurred during interpretation and reporting, where QUAN and QUAL data sets were merged using a joint
display technique called the Pillar Integration Process (PIP). Figure 1 provides a summary of the two phases of data integration.

**Figure 1**

*Summary of Two Phases of Data Integration*

```
<table>
<thead>
<tr>
<th>Phase 1 Data Integration:</th>
<th>Phase 2 Data Integration:</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Survey questions informed interview questions</em></td>
<td><em>QUAN and QUAL findings merged using PIP, a joint display technique.</em></td>
</tr>
<tr>
<td>Quantitative data analysis using descriptive statistics</td>
<td></td>
</tr>
<tr>
<td>Qualitative data analysis using inductive thematic analysis</td>
<td></td>
</tr>
</tbody>
</table>
```

**Pillar Integration Process (PIP)**

The Pillar Integration Process (PIP) is a four-stage analytical technique to integrate mixed-method data (Johnson et al., 2019). The PIP was developed to address a gap between researchers’ theoretical understanding of data integration and the practical how-to-steps of achieving data integration (Fetters & Freshwater, 2015; Johnson et al., 2019). The four-stages of PIP are listing, matching, checking and pillar building, which are completed after initial quantitative and qualitative analysis. Figure 2 is a slightly adapted illustration of Johnson et al.’s (2019, p.305) figure of the four-stages of data integration using PIP.
Figure 2

Illustration of Data Integration Using the Pillar Integration Process (PIP)

Each stage used to integrate QUAN and QUAL data using PIP is described below:

1. Listing: After initial descriptive statistical analysis of survey data (QUAN) and thematic analysis of interview data (QUAL), raw data (e.g. percentages and selected quotes) were listed in the QUAN Data and QUAL Quotes columns. Next, QUAN categories and QUAL sub-themes identified from initial analysis were entered in the corresponding columns.

2. Matching: Once relevant data were listed in the QUAN and QUAL columns, entries between QUAN and QUAL columns were matched horizontally to align similar data. This procedure of matching similar data worked to refine and organize categories between the two data sets to identify “patterns, parallels, similarities, or any other relational quality” (Johnson et al., 2019, p.305). When no match was found, then the heading “not identified” was used to visually represent gaps in match data.

3. Checking: In this stage of data integration, matched data is checked for quality and accuracy. Any identified gaps were verified to improve the quality of data integration.
This stage was of particular importance because it served as an additional checkpoint to pause and reflect on QUAN and QUAL data both separately and in relation to each other to identify emerging patterns.

4. **Pillar Building:** Findings identified from the listing, matching, and checking stages were compared to build the pillar of integrated findings from QUAN and QUAL data collection. Each of the integrated themes listed in the pillar is constructed from each row of matched findings in the QUAN and QUAL columns. The findings in the pillar represent the weaved together viewpoints of students and are used to build a narrative of students’ school experiences.

The benefit of using PIP is that it synthesizes different data sources using a multi-stage technique. Consequently, allowing researchers to convey each step of the data integration process, thus promotes transparency and replicability. Additionally, the PIP enables researchers to identify instances of divergence, which are also beneficial in generating new insights on the phenomenon being investigated (Johnson et al., 2019).

**Ethical Considerations**

*Informed Consent and Assent*

To date, few studies examine effective methods to obtain consent from individuals with communication difficulties (Loyd, 2013; Jordan & Preece, 2010) or developmental disabilities, including autistic youth (Harrington et al., 2014). However, the research gap does not mean that autistic individuals cannot give informed consent and assent (Loyd, 2013), but rather the strategies to engage autistic and other hard to reach populations are limited. This reported limitation calls for researchers to make intentional efforts to provide meaningful and alternative...
options (Scott-Barrett et al., 2019; Loyd, 2013), including an ongoing process of assent (British Psychological Society, 2014).

According to the new *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS 2, 2018), participants between the ages of 14-17 years old may qualify as mature minors and they should be provided with the adult/participant consent form, if they possess decision-making capacity. Following this TCPS consideration, and in alignment with recommendations from researchers familiar with eliciting the views of autistic students, in my study, autistic participants were viewed from a strength-based lens with presumed competence (Scott-Barrett et al., 2019). Participants that met the study’s eligibility criteria, were considered to possess decision-making capacity to provide consent, therefore parental consent was not required in my study.

Participants were invited to download a printable information booklet that introduced the researcher, described the research, eligibility, participation requirements, and risks and benefits of participating in the research. The booklet was carefully formatted to convey study information in a simple, concrete manner, paired with visual supports (Harrington et al., 2014; Loyd, 2013). If parents were interested in learning about the study, a short parent document was also available for download. Once a participant read the research information booklet, they returned to the online survey to mark their consent. If they consented, the survey started, and if they did not consent, the survey closed. Ascent was checked at regular intervals (Loyd, 2013), including at the beginning of the survey and throughout the email interview.

**Risk**

There were no known risks for participating in this study. Students were not observed in their educational setting; therefore, the study was not obtrusive or changed school behaviours
Methodology

(Zeni, 1998). Students were able to respond to the questions in their own space, in their own time, and with supports if required. If a participant decided to participate in the semi-structured email interview, they might have felt tired, which they could take breaks or end the interview at any time. If participants felt tired or stressed during or after participating in the research, they were encouraged to contact the Crisis Text Line; however, there were no known occurrences of stress or crisis.

Confidentiality and Anonymity

There was no intentional collection of data related to names, date of birth, and address. Some participants may have signed their names at the end of email correspondence; however, this information was subsequently removed from email transcripts following the interview. Survey data is untraceable to participants, and both quantitative and qualitative data is stored on secure, password-protected servers for five years.

Researcher-Participant Relationship

There was no known relationship between the researcher and participants. No recruitment activities were completed in connection to my involvement with various school boards. Interaction with participants was initiated by the participant and occurred via email to schedule and complete the email interview.

Ownership of Data

All data will be kept for five years following the results’ initial publication and then will be destroyed. Any future use of this research data is required to undergo review by a Research Ethics Board. A summary of the research was provided to one participant, one autistic self-advocacy group, one community agency, and two school superintendents, in response to their individual requests.
Validity, Reliability, Trustworthiness, Treatment and Integrity

Validity and Reliability

The validity and reliability of data are grounded in a study’s methodological design and the tools and processes used to collect data (Abowitz & Toole, 2010; Leung, 2015). Since this study sought first-person perspectives, it was important that participants independently chose to participate in the research and that flexible options to enable authentic participation were available to students throughout the study. Therefore, removing barriers for autistic students to access and participate in the research by offering synchronous and asynchronous involvement strengthened the validity and reliability of quantitative and qualitative data collected.

Additionally, the mixed-method convergent parallel design of the study meant that data could be viewed from quantitative and qualitative perspectives (Leung, 2015). Subsequently, different tools, including the asynchronous online survey and the synchronous email interview, helped to confirm the data’s validity and reliability. As previously described in the section titled: Data Collection, items from the Panorama Survey (Gehlbach, 2014) were used to develop the online survey and informed the semi-structured email questions. The Panorama Survey (Gehlbach, 2014) is proven to have strong structural validity and reliability (Geiger & Amerin-Beardsley, 2019), and upon completing Chronbach’s Alpha, the test scales have strong internal consistency ($\alpha=0.825$). Therefore, the Panorama Survey’s (Gehlbach, 2014) customizable features also contributed to the validity and reliability of student perception data collected.

The validity of qualitative data is demonstrated by the semi-structured interview questions’ suitability to explore the phenomena while respecting preferences for non-speaking communication, cultural, and gender identities. Additionally, the composition of semi-structured email questions was considered in the context of the previous research on autistic students’
school experiences and research on ethical methods to engage autistic children, youth, and adults in research. Lastly, the reliability and validity of quantitative and qualitative data sets were tested by triangulating data (Abowitz & Toole, 2010) using the PIP process.

A well-documented audit trail to support the validity and reliability of data includes:

a) Recruitment logs, including contacts, responses, and timelines.

b) Email transcripts tracking correspondence with participants to schedule interviews, semi-structured interview questions used, participant responses, and time/date stamps.

c) Qualtrics generated reports on survey data.

d) Excel spreadsheets of mean and standard deviations of survey data; and

e) Line by line coding of email transcripts.

**Trustworthiness**

The trustworthiness of quantitative and qualitative data was achieved through the following four domains:

1. Credibility is the extent to which the source of the data accurately represents what the data is supposed to represent (Aroh, 2014). The credibility of quantitative and qualitative data was achieved through triangulation between the survey data, open-ended survey data, interview data, and previous research on the self-reported school experiences of autistic students.

2. Transferability is how well the data would apply to other instances (Guba & Lincoln, 1985) and was achieved by comparing integrated findings with previous research on the self-reported school experiences of autistic students.
3. Confirmability is the extent in which data is free from researcher bias (Guba & Lincoln, 1985) and was achieved by providing an audit trail of data collection, analysis and interpretation of the data, methodological selection, data analysis, and interpretation; and
4. Dependability is how likely the data can be replicated in another study (Denscombe, 2010) and is supported by providing a clearly defined audit trail, or map, of the decision-making process and procedures used from the initial conceptualization of the research, data analysis, and discussion (see Appendix B: Research Pathway).

The degree in which the research inspired personal and social change, also known as catalytic validity (Lather, 1986), was done through researcher reflexivity, researcher actions to meet the unique needs of autistic participants, and insights presented to educators and policymakers in the Discussion, Recommendations, and Conclusions chapter.

**Treatment and Integrity**

Through a critical disability theoretical framework and a phenomenologically informed research lens, this research aimed to increase the visibility and recognition of autistic voice while resisting objectification through Othering (Ahmed, 2002; Krumer-Nevo & Sidi, 2012). There are several actions I took to support my efforts, including researcher reflexivity and memo-writing. For example, there was a moment while conducting an email interview where I found myself questioning the appropriateness of time between asking and receiving student responses to my questions. My impatience led me to wonder about technology issues, distractions, but mostly participant ability. However, by writing down and reflecting on my thoughts, I realized that it was easier and perhaps more commonplace, for me to direct my feelings of tension towards the autistic student than it was to re-evaluate my views and assumptions on legitimate knowledge production in relation to the concept of time. Other ways I sought to improve the ethical integrity
of this study was by offering an online platform to collect student perception data, which was beneficial because it acknowledged and supported the unique and individual thinking, sensory, social, and communicative preferences of autistic participants. Additionally, virtual engagement with participants helped minimize power differentials and implicit expectations to follow “socially acceptable” behaviours and interactions. Lastly, by using unaltered student quotations to support my interpretation of students’ school experiences, the research spotlight remained centred on the voice and views of autistic students (Krumer-Nevo & Sidi, 2012).

**Chapter Summary**

This chapter began by connecting my ontological and epistemological researcher position with my rationale for using a critical disability theory framework and a phenomenological informed research lens to learn about autistic students’ school experiences. The remainder of the chapter described the research design including a justification for using a mixed-method convergent parallel research design within a critical disability theory framework; a description of the research setting, sample, and data sources; data collection methods and instruments; ethical considerations; validity, trustworthiness, treatment, and integrity; and limitations and delimitations of the study.
Chapter 4: Analysis and Findings

This chapter presents the sequential comparative analysis of quantitative data from the online survey (n=72) and qualitative data from the open-ended survey question (n=19), and semi-structured email interview (n=10). Sequential comparative analysis is an effective approach to combine quantitative and qualitative data in mixed-method research to explore relationships between different data sets (Kane et al., 2014). The first stage of analysis occurred when quantitative data were analyzed using descriptive statistics and qualitative data were analyzed using inductive thematic analysis. Lastly, to provide a synthesis of research findings, quantitative and qualitative data sets were merged using a joint display technique called the Pillar Integration Process (PIP).

Summary of Study Findings

Based on the self-reports of autistic high school students, this study identified the following five main findings:

1. Teacher Characteristics: Teachers who are respectful, understanding, caring, friendly, fun, real and relatable, and passionate about teaching help to create a sense of belonging for autistic students.

2. Pedagogical Practices: Autistic students value teachers who personalize learning by using flexible pedagogical practices and appreciate when teachers check-in to ensure they understand the material.

3. School Environment: Autistic students seek personalized school spaces to accommodate their unique sensory preferences and to help reduce their feelings of stress and anxiety.

4. Peer Relationships: Autistic students desire peer recognition, acceptance, and support.
Analysis and Findings

5. Modes of Communication: Autistic students use different modes of speaking and non-speaking communication as a strategy to improve the clarity of their messages and to minimize feelings of stress and anxiety.

Quantitative Data Analysis

Descriptive statistics is the statistical description of the properties of a data set. Typical reports include the mean, median, mode, variance, and standard deviation (Creswell, 2014). Focusing on two analytical components of descriptive statistics, specifically mean and standard deviation of students’ survey responses, was suitable because this study did not seek to test a hypothesis or compare within-subject experiences. However, future consideration of completing a statistical analysis of variance would be worthwhile to investigate the relationship between students’ responses in particular survey items. Calculating the mean of student responses was advantageous because it supported the four-phases of data integration outlined by PIP. Thus, the quantitative analysis results were transferred into the QUAN Data pillar in Table 7, titled Integration of Quantitative Data and Qualitative Data Using the Pillar Integration Process, which follows the presentation of qualitative data in this chapter.

The survey items were Likert-type scales (Sullivan & Artino, 2013), where participants chose a response from a four-point Likert scale or a five-point Likert scale, with an option of “I prefer not to answer” included on each item. There were 14 survey items that provided four-point Likert scale options and four survey items that provided five-point Likert scale options. Table 4 summarizes the mean and standard deviation (SD) for the 14 survey items with four-point Likert scales, and Table 5 summarizes the mean and SD for the four survey items with five-point Likert scales. A synthesis of survey responses follows Table 4 and Table 5.
### Table 4

**Mean and SD of Survey Responses with Four-Point Likert Scale**

<table>
<thead>
<tr>
<th>Survey Questions</th>
<th>Almost Always</th>
<th>Often</th>
<th>Once in a While</th>
<th>Almost Never</th>
<th>Prefer not to Answer</th>
<th>M</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you receive feedback at school?</td>
<td>15%</td>
<td>46%</td>
<td>28%</td>
<td>10%</td>
<td>1%</td>
<td>2.64</td>
<td>0.87</td>
<td>72</td>
</tr>
<tr>
<td>How interesting is school?</td>
<td>29%</td>
<td>36%</td>
<td>27%</td>
<td>7%</td>
<td>1%</td>
<td>2.82</td>
<td>0.97</td>
<td>72</td>
</tr>
<tr>
<td>How excited are you to go to school?</td>
<td>27%</td>
<td>24%</td>
<td>24%</td>
<td>25%</td>
<td>0%</td>
<td>2.52</td>
<td>1.14</td>
<td>71</td>
</tr>
<tr>
<td>How eager are you to participate in your classes?</td>
<td>24%</td>
<td>18%</td>
<td>34%</td>
<td>23%</td>
<td>1%</td>
<td>2.41</td>
<td>1.13</td>
<td>71</td>
</tr>
<tr>
<td>How often do your teachers take the time to ensure you understand the material?</td>
<td>19%</td>
<td>40%</td>
<td>26%</td>
<td>14%</td>
<td>1%</td>
<td>2.60</td>
<td>1</td>
<td>70</td>
</tr>
<tr>
<td>How much do your teachers encourage you to do your best?</td>
<td>34%</td>
<td>43%</td>
<td>20%</td>
<td>2%</td>
<td>0%</td>
<td>3.13</td>
<td>0.78</td>
<td>70</td>
</tr>
<tr>
<td>Overall, how high are your teachers’ expectations of you?</td>
<td>26%</td>
<td>47%</td>
<td>19%</td>
<td>7%</td>
<td>1%</td>
<td>2.89</td>
<td>0.93</td>
<td>70</td>
</tr>
<tr>
<td>How many of your teachers are respectful towards you?</td>
<td>39%</td>
<td>43%</td>
<td>15%</td>
<td>3%</td>
<td>1%</td>
<td>3.14</td>
<td>0.87</td>
<td>70</td>
</tr>
<tr>
<td>How many of your teachers would you be excited to see again in the future?</td>
<td>19%</td>
<td>37%</td>
<td>33%</td>
<td>11%</td>
<td>0%</td>
<td>2.63</td>
<td>0.92</td>
<td>70</td>
</tr>
<tr>
<td>Overall, how much do you feel like you belong at your school?</td>
<td>29%</td>
<td>31%</td>
<td>21%</td>
<td>19%</td>
<td>0%</td>
<td>2.70</td>
<td>1.08</td>
<td>70</td>
</tr>
<tr>
<td>How well do peers at your school understand you as a person?</td>
<td>20%</td>
<td>29%</td>
<td>30%</td>
<td>21%</td>
<td>0%</td>
<td>2.47</td>
<td>1.05</td>
<td>70</td>
</tr>
<tr>
<td>How much respect do your peers in your school show you?</td>
<td>24%</td>
<td>41%</td>
<td>26%</td>
<td>7%</td>
<td>1%</td>
<td>2.80</td>
<td>0.94</td>
<td>70</td>
</tr>
<tr>
<td>How often do you worry about bullying at school?</td>
<td>13%</td>
<td>20%</td>
<td>41%</td>
<td>24%</td>
<td>1%</td>
<td>2.19</td>
<td>1</td>
<td>70</td>
</tr>
<tr>
<td>How often do you worry about online bullying?</td>
<td>9%</td>
<td>17%</td>
<td>45%</td>
<td>26%</td>
<td>3%</td>
<td>2.03</td>
<td>0.95</td>
<td>70</td>
</tr>
</tbody>
</table>

### Table 5

**Mean and SD of Survey Responses with Five-Point Likert Scale**

<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Extremely</th>
<th>Quite</th>
<th>Somewhat</th>
<th>Slightly</th>
<th>Not</th>
<th>Prefer not to Answer</th>
<th>M</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>How comfortable are you asking questions about what you are learning?</td>
<td>19%</td>
<td>24%</td>
<td>28%</td>
<td>17%</td>
<td>11%</td>
<td>1%</td>
<td>4.1</td>
<td>2.7</td>
<td>72</td>
</tr>
<tr>
<td>How fair or unfair are the rules at school?</td>
<td>26%</td>
<td>31%</td>
<td>22%</td>
<td>13%</td>
<td>8%</td>
<td>0%</td>
<td>4.60</td>
<td>2.78</td>
<td>72</td>
</tr>
<tr>
<td>How pleasant or unpleasant is the physical space at your school?</td>
<td>31%</td>
<td>28%</td>
<td>14%</td>
<td>16%</td>
<td>11%</td>
<td>0%</td>
<td>4.76</td>
<td>2.99</td>
<td>71</td>
</tr>
<tr>
<td>How positive or negative is the energy at school?</td>
<td>31%</td>
<td>27%</td>
<td>14%</td>
<td>23%</td>
<td>4%</td>
<td>1%</td>
<td>4.92</td>
<td>2.97</td>
<td>71</td>
</tr>
</tbody>
</table>
Synthesis of Students’ Survey Responses

To provide a synthesis of students’ survey responses, survey items measuring similar themes were organized into one of three main categories. Each category’s composition reflects the survey scales that each survey item belonged to in Panorama Survey (Gehlbach, 2014). For example, the survey item “How often do you receive feedback at school?” was selected from the survey scale titled Pedagogical Effectiveness. The three main categories used to present a synthesis of students’ responses on the 18 survey items are:

1. Pedagogical Effectiveness, Rigorous Expectations and Student-Teacher Relationships
2. Valuing School and School Engagement
3. School Belonging, School Safety and School Climate

**Pedagogical Effectiveness, Rigorous Expectations and Student-Teacher Relationships**

Slightly more than half of the students indicated that their teachers provide feedback (61%) and take the time to ensure they understand the material (59%) almost always and often. Less than half of students (43%) reported feeling extremely and quite comfortable asking questions. Contrastingly, nearly three-quarters of students reported that their teachers had high expectations (73%) and encouraged (77%) them to do their best almost always and often. While most students (82%) felt respected by their teachers almost always and often and very few students (3%) felt disrespected by their teachers and slightly more than half of the students (56%) reported that they would be excited to see their teachers in the future. Overall, most autistic students reported feeling respected by their teachers and that their teachers were encouraging and had high expectations of them. However, slightly more than half of the students also reported that their teachers did not provide enough feedback and did not feel comfortable asking questions.


**Valuing School and School Engagement**

While students were equally divided in their excitement to attend school (Almost Always=27%, Often=24%, Once in a While=24%, Never=25%), nearly two-thirds of students (65%) reported that their school experiences were interesting almost always and often. Less than half of students (42%) reported feeling eager to participate in class almost always and often, while nearly a quarter of students (23%) reported almost never feeling comfortable participating in class. Survey data on students feeling eager to participate in class (42%) is similar to survey data on students feeling comfortable asking questions (43%) in class, where approximately four in ten students felt comfortable. Overall, half of autistic students were excited to go to school, two-thirds of students found school interesting and nearly a quarter of students do not feel comfortable participating and asking questions in class.

**School Belonging, School Safety and School Climate**

Slightly over half of students (60%) reported that they almost always and often felt like they belonged at school, and 19% of students almost never felt like they belonged at school. Slightly over half (57%) of students felt the school rules were extremely and quite fair, and 8% of students felt that the school rules were not fair. While 65% of students reported feeling respected by their peers almost always and often, slightly less than half (49%) of students felt that their peers understood them as a person almost always and often. Nearly a quarter (21%) of students reported that their peers almost never understood them as a person. One-third of students indicated that they worried about in-school bullying (33%) almost always and often, and slightly over a quarter of students worried about online bullying (26%) almost always and often. Most students reported worrying about in school (41%) and online (45%) bullying once in a
while, and nearly a quarter of students reported almost never worrying about in school (24%) or online (26%) bullying.

Fifty-nine percent of students reported that their school spaces were extremely and quite pleasant, and almost the same number of students (58%) felt similarly about their school’s energy. Contrastingly, 11% of students felt that their school spaces were not pleasant, and 4% felt that the school energy was not positive. Overall, slightly more than half of the students felt a sense of school belonging and respected by their peers. However, less than half autistic students felt that their peers understood them as a person. Nearly three-quarters of students worried about school or online bullying and slightly more than half of students were pleased with their school environment.

**Qualitative Data Analysis**

Qualitative data were analyzed using inductive thematic analysis. Inductive thematic analysis offers a set of techniques to analyze texts and explain main or frequent ideas, topics or themes within a collection of data. Inductive thematic analysis was an appropriate analytical tool to use because it avoided a priori theory and generated themes from the “bottom-up” opposed to the “top-down” (Braun & Clarke, 2006, p.12). This meant that qualitative themes remained strongly connected to students’ self-reports and were less influenced by my researcher assumptions and interest in the phenomenon (Braun & Clarke, 2006). Additionally, my interpretation of autistic students’ school experiences was not compared to “typical” students’ experiences. Which is a problematic research practice because it perpetuates us-them type thinking (Krumer-Nevo & Sidi, 2012) and reinforces educator views that equate difference with deficit and rationalizes oppressive school practices such as labelling autistic students as “special education” students.
Analysis and Findings

Qualitative data from the open-ended survey responses (n=19) and the semi-structured email interview (n=10) were analyzed together by following six stages: 1) Familiarizing myself with data, 2) Generating initial codes, 3) Searching for themes, 4) Reviewing themes, 5) Naming themes, and 6) Writing themes (Braun & Clarke, 2006). To familiarize myself with the qualitative data, I read open-ended survey responses and email transcripts several times and noted my thoughts and questions in a separate document or directly on the survey responses and email transcripts. This metacognitive process was beneficial because it allowed me to reference and reflect on my researcher assumptions and ableist biases, including the concept of time and quantity of words in participants’ typed responses. In a word document, I combined the open-ended survey responses with the email transcripts and added two columns to the right of the transcripts. The first column is where I generated initial codes from line-by-line analysis, and the second column is where I recorded names of sub-themes based upon line-by-line analysis. Table 6 provides a sample of the process of inductive thematic analysis I used to analyze qualitative data.
Table 6

Sample of Inductive Thematic Analysis

<table>
<thead>
<tr>
<th>Interview Data</th>
<th>Line-by-line</th>
<th>Sub-Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ok, thanks for the clarification. The reason why I selected “other” was</td>
<td>Draw to communicate, ask questions, seek teacher attention</td>
<td>modes of communication</td>
</tr>
<tr>
<td>because for me personally I use a mix of all the above mentioned and I</td>
<td>Flexible communication methods</td>
<td></td>
</tr>
<tr>
<td>also communicate through art, specifically drawing out my questions or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>answers. Hope this clarifies my selection of choice.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>During lunch we would mainly talk random stuff going on in each others</td>
<td>Social connection during unstructured school time</td>
<td>peer relationships</td>
</tr>
<tr>
<td>lives and tell jokes to each other but we would also hang out on sundays</td>
<td>Humour, hang out with friends on weekends to play games</td>
<td>peer support</td>
</tr>
<tr>
<td>due to it being the only day we all weren't busy were we would play</td>
<td>Routine gatherings with friends outside of school</td>
<td></td>
</tr>
<tr>
<td>videogames, card/ board games, and dungeons and dragons. And I am</td>
<td></td>
<td></td>
</tr>
<tr>
<td>happy to say that we still hang out every Sunday to do the activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>mentioned above.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I think a good characteristic in a teacher would be that they seem really</td>
<td>Interested about subject matter</td>
<td>friendly, kind, sense of humour</td>
</tr>
<tr>
<td>interested in the subject they are teaching as well as being openly</td>
<td>Friendly, sense of humour</td>
<td>passionate about teaching/subject,</td>
</tr>
<tr>
<td>friendly and have a sense of humor. In grad 12 biology I had a great</td>
<td>Enthusiastic, tell stories</td>
<td>relatable</td>
</tr>
<tr>
<td>teacher who would always be enthusiastic and tell stories from previous</td>
<td></td>
<td></td>
</tr>
<tr>
<td>years and from his earlier life as well as being very kind and funny.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School spaces were usually not a problem for me but I tended to avoid</td>
<td>Noisy, crowded</td>
<td>-sensory</td>
</tr>
<tr>
<td>the cafeteria because it was noisy and there were a large amount of</td>
<td>Friends lockers, quiet</td>
<td>-personal spaces</td>
</tr>
<tr>
<td>students. For places I would like to go to were mainly my friends lockers</td>
<td>hallways</td>
<td></td>
</tr>
<tr>
<td>were we would hang out in the more quiet hallway.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Thus, based on inductive thematic analysis of the 19 open-ended survey responses and ten semi-structured interviews, 23 sub-themes were identified as relevant to autistic high school students’ school experiences. The presentation of sub-themes is grouped based on their relatedness to each other. For example, sub-themes related to sensory experiences, are grouped together, and sub-themes relating to experiences with peers are grouped together. The 23 sub-themes are:

a) Experiences with Teachers (13 sub-themes): Understanding, caring, friendly, accepting, respectful, honest, patient, sense of humour, passionate about subject matter, relatable, flexible, checks-in, personalizes learning

b) Experiences with Peers (3 sub-themes): acceptance, support, recognition
c) Sensory Experiences (3 sub-themes): personal spaces (quiet, small, open), social impact, stress and anxiety
d) Communication Experiences (4 sub-themes): modes of communication, time to think, accuracy of messages, minimize stress and anxiety

Each of the sub-themes and supporting student quotations were transferred into the QUAL Quotes and QUAL Sub-Themes pillar in Table 7, titled Integration of Quantitative Data and Qualitative Data Using the Pillar Integration Process, which follows the interpretation of qualitative sub-themes in this chapter. The 23 sub-themes were identified as either positively or negatively impacting autistic students’ school experiences.

**Qualitative Sub-Themes**

*Experiences with Teachers*

The 13 sub-themes that emerged from autistic students’ experiences with teachers highlight that autistic students value teachers who are understanding, caring, friendly, accepting of their differences, patient, respectful, relatable, honest, have a sense of humour and are passionate about teaching. It’s important to note that quotations have not been edited and are presented as initially typed by students during the email interview. The following quotes illustrate autistic students’ views on their experiences with teachers:

“I really appreciated understanding, caring and friendly characteristics. In addition, I felt welcomed being trusted by teachers.” (Zia)

“They are Respectful of you and value you as a person even though you have limitations. They are Honest and don't tell “white lies” because they care more about your feelings than the future consequences or your understanding.” (Charlie)
“The ones that stand out to me are the ones who would loudly praise or compliment me for doing well on some assignment, were patient with me when I would ask them to explain some concept I had trouble understanding, and would greet me with a smile if I happened to pass by them in the hallway.” (Alex)

“I don’t really like to ask questions in class, but would ask after the class was over to go over somethings I wasn’t good at or clear on. The best teachers I had didn’t feel like I was bothering or annoying them”. (Frankie)

“he would always be enthusiastic and tell stories from previous years and from his earlier life as well as being very kind and funny...and do a magic trick every Friday. he simply made all the students in the class in love with his course. he used to talk to the students about other stuff besides the lesson like he is one of our friends.” (Azariah)

From the sampling of student quotations, we learn how precisely autistic students pinpoint the actions teachers take that either support or hinder the development of positive relationships, ultimately leading to students’ overall sense of school belonging. The recalling of personally memorable moments with teachers, where autistic students are made to feel accepted and respected, emphasizes the central role teachers play in creating inclusive school environments outside the pragmatics of teaching and learning.

**Experiences with Peers**

Peer recognition, peer acceptance, and peer support were three areas identified by autistic students as important to their school experiences. Of the four email participants who shared examples relating to in-school friendships, two reported positive experiences. One student shared friendships were difficult, and the fourth student seemed indifferent towards connecting with peers outside of his regular friend group. For example, Azariah stated that he liked to spend his
lunchtime watching football with his friends, and Taylor shared that “it was difficult to build and maintain friendships” due to his “less than stellar social skills”. Frankie shared that he neither felt respected nor disrespected by peers outside of his friend group, but this was due to his “shy and quiet nature”. The following quotations provide additional insights into autistic students’ views on their experiences with peers:

“A student I wasn't very familiar with approached me and said, “Wow, I had no idea you were so smart.” I appreciated them saying that to me, though maybe they had a negative first impression? (Sam)

“Someone who doesn’t treat you differently but understands your weaknesses” (Zia)

“During lunch we would mainly talk random stuff going on in each others lifes and tell jokes to each other but we would also hang out on sundays due to it being the only day we all weren't busy were we would play videogames, card/ board games, and dungeons and dragons. And I am happy to say that we still hang out every Sunday to do the activities mentioned above” (Armani)

“One of the other kids in that group was teasing me about my shirt. I dont like to be teased (who does). But the nice girl stepped in and told the other girl to stop it, and that I looked nice. I've had more respect for her since then.” (Kai)

Autistic students also conveyed that they appreciated peers who recognized the similarities between them, rather than disparities or differences. However, autistic students acknowledged that when “weaknesses” were evident, they valued peers who accepted their vulnerabilities without stigmatizing their differences. Additionally, autistic students shared that they appreciated receiving peer support in instances of teasing and that they felt more respect for peers after receiving peer assistance and validation.
**Sensory Experiences**

Autistic students consistently made connections between school spaces and their feelings of stress, anxiety, and overall sense of school belonging. These qualitative findings are similar to quantitative survey results that indicate slightly over half of the participants feel that their school spaces (59%) and school energy (58%) are pleasant almost always and often. While most students shared similar views on school spaces, they liked and disliked; two students held opposing opinions about dark spaces. However, the disparity seemed to be predicated on the intended use of the space. For example, one student liked the calming effect of dark spaces while the other student did not like to talk to peers in dark and secluded spaces because it made him feel “weird” and “awkward”. Charlie provided a detailed explanation of how school spaces significantly impacted her sense of safety and wellbeing:

> I avoid as much as I can

1) **open spaces or busy spaces because there is so much going on that I can't focus on anything. I get anxious that someone will come up and talk to me or ask me for something and I won't notice them (I wear earplugs much of the time that many people either don't notice or assume are music/hearing aids or something), and there are usually a ton of sounds and smells and textures and colours.**

2) **Rooms with florescent lights. They buzz and flicker and are usually too bright. Need I say more?**

3) **Places people are eating. Cafeterias, public spaces around mealtimes. Many people chew with their mouths open or eat messily or talk with food in their mouths and no matter how much I like those people the sensory experience of being near that is very off-putting. This doesn't just apply at school- I've had this problem with my own family at the dinner**
table too. I used to leave because it was too much and then maybe not eat but now I just eat separately from them.

4) Crowded spaces where I will be forced to enter other people's personal space or they enter mine. Never mind that in high school, some people think that perfume/cologne = a showered clean body smell. No. Now you have two bad smells.

I enjoy/ spend time in

1) Libraries, as they are usually uncrowded, quiet (full bookshelves are great sound absorbers) and slow-paced. People typically mind their own business and are often banned from eating or drinking or talking too loud. It's fantastic!

2) Bathroom stalls. They aren't too great - typically fluorescent lights and bad smells/sights but the good part is you can lock yourself in and no one will bother you if you need a break. I used to lock myself in and break down when I was having a hard time and then pull myself together and go back to being Totally Fine. It helps avoid a lot of the stigma associated with crying or having sensory overload at school because if no one knows, you don't need to explain yourself.

3) Any place that can be made dark, quiet, and private. Sometimes this was a teacher's office, a storage closet, or when I was younger, at recess, a tree or bush. Even though a tree isn't always dark or quiet, leaves (especially in wind) make a very soothing noise, and no one sees you when you're so far above eye level.

Three students shared that the organization of classroom desks also affected their feelings of anxiety and comfort when interacting with peers. For example, Lennon shared “I prefer a classroom with symmetry and desks all facing the same way. classrooms with desks in random
or weird orientations would distract me or make me anxious”. Alex also expressed that he felt anxious if desks were positioned to face each other:

'It’s the kind where desks are positioned and connected in a way so that each person is face to face with each other. Like a group of 3-4 desks connected to each other to form a group of students I had that in some of my classes, and I disliked it very much. I felt very anxious and awkward facing the person in front of me, and would always try to avoid eye contact as much as I could with them. I much prefer the common desk layout where its just individual desks organized in rows.

Frankie typed out a seating chart to show me where she preferred to sit in a classroom:

'I prefer to sit on the edge, and in the 2nd to last row, and preferably close to the door.

For example:

FRONT OF THE ROOM

x x x x x x x x x

x x x x x x x x x

x x x x x x x x x x A

x x x x x x x x x x DOOR

I try to sit where “A” is

Frankie's preferred location, “A”, could be interpreted as ideal for several reasons. First, sitting at the end of a row minimizes closeness with other students, hence reduces sensory input and expectations for social interactions. Second, support from teachers could occur promptly with little notice from peers. Third, if Frankie felt she needed to leave the classroom, she could exit discreetly, thus minimizing peers’ unwanted attention.
It is undeniable that school and classroom spaces have an extensive impact on autistic students’ feelings of physical and psychological safety and learning ability. When autistic students are continually expected to navigate oppressive learning environments, they have fewer cognitive resources available to learn new concepts, express their learning, and connect with teachers and peers.

**Communication Experiences**

Autistic students’ reports on their school experiences related to their preferred mode of communication were incredibly exciting and thought-provoking. I am effectively confirming this study’s strong catalytic validity, where both personal and institutional change is spurred. Admittedly, even as an experienced educator, I was unaware of the number of autistic students who preferred to use non-speaking modes of communication. Furthermore, I was not in-tune with the internal and external circumstances that guided students’ choices on their selection of non-speaking methods of communication, including typing and drawing. Consequently, I have begun to weave this new knowledge into my leadership conversations and the processes and systems I create to support teachers and autistic students. Very little research has been conducted on the use of multi-modal communication by autistic students in inclusive settings, thus partially explaining the lack of educational discourse that considers effective pedagogical practices to support non-speaking representations of knowledge.

Interestingly, several autistic students shared that they preferred to use various non-speaking modes because the method provided additional time to think, improved the accuracy of messages, and minimized feelings of stress and anxiety. The following quotes highlight autistic students’ preferences for using non-speaking modes of communication:
“If I were to have a question I'm not sure how to answer or word I would just draw it out. As for questions I use my drawing to gather the attention of my teachers when they pass by my desk and see if I made progress and see a giant convoluted cartoon which basically us requesting help because I get anxious putting up my hand and asking loudly my question.” (Lennon)

“No, I do not use an assistive communication device. I put typing as my preferred method of communication because I often have trouble coming up with words on the spot when I am talking in person. Like I am always stumbling over my words or stuttering. When I type, I can edit and review what I have to say until it is something that I feel is satisfactory.” (Alex)

“I like to think about my answer first, and be able to type it out and change it if I want to. In person or talking can be stressful sometimes if I don't know how to answer the question or what I want to say.” (Frankie)

Similar to autistic students’ views on their experiences with teachers, peers, and school environments, autistic students share with great detail their rationale for using non-speaking modes of communication, including typing and drawing. This reflective awareness reveals a deep understanding of autistic self and autistic self in relation to others. This attentiveness highlights the desire and the commitment of autistic students to conform to the rules that govern schools to feel accepted and have a sense of belonging.

**Integration of Quantitative Data and Qualitative Data**

After completing the initial quantitative and qualitative data analysis, quantitative categories and qualitative sub-themes are merged using the Pillars of Integration Process (PIP), which uses a four-stage integration process (Johnson et al., 2019). The four-stages of data
integration include listing, matching, checking, and pillar building. The PIP is beneficial because it provides a visual method to draw out insights beyond what is represented in separate quantitative and qualitative results (Fetters et al., 2013); and offers more in-depth explanations of the phenomena under study— in my case, the self-reported school experiences of autistic participants. Table 7 illustrates the PIP process used to integrate quantitative and qualitative data sets and highlights the five main study findings in the center column named Research Findings.

Table 7

**Integration of Quantitative Data and Qualitative Data Using Pillar Integration Process**

<table>
<thead>
<tr>
<th>QUAN Data</th>
<th>QUAN Categories</th>
<th>Research Findings</th>
<th>QUAL Sub-Themes</th>
<th>QUAL Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online Survey (n=73)</td>
<td>respected, encouraged, school belonging</td>
<td>Teacher Characteristics</td>
<td>understanding, caring, friendly, accepting, respectful, honest, patient, sense of humor, passionate about subject matter, relatable</td>
<td>“I really appreciated understanding, caring and friendly characteristics. In addition, I felt welcomed being trusted by teachers.”</td>
</tr>
<tr>
<td>Teacher Characteristics</td>
<td>flexible, personalized adaptations, checks for understanding</td>
<td>“I don't really like to ask questions in class, but would ask after the class was over to go over somethings I wasn't good at or clear on. The best teachers I had didn't feel like I was bothering or annoying them.”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

72% of students feel respected by their teachers.
77% of students feel teachers encouraged them to do their best.
60% of students feel like they belonged at school.
61% of students feel teachers provide feedback.
59% of students feel teachers ensure they understand the material.
73% of students feel teachers had high expectations of them.
42% of students feel eager to participate in class.
43% of students feel comfortable asking questions in class.
51% of students feel excited to attend school.
65% of students feel school is interesting.
| Study Findings | Based on the integration of quantitative categories and qualitative themes using PIP, this study identified five main findings being central to autistic students’ school experiences. The five main study findings are: |
1. Teacher Characteristics: Teachers who are respectful, understanding, caring, friendly, fun, real and relatable, and passionate about teaching help to create a sense of belonging for autistic students.

2. Pedagogical Practices: Autistic students value teachers who personalize learning by using flexible pedagogical practices. Students also appreciate when teachers check-in to ensure they understand the learning material.

3. School Environment: Autistic students seek personalized school spaces to accommodate their unique sensory preferences and to help reduce their feelings of stress and anxiety.

4. Peer Relationships: Autistic students desire peer recognition, acceptance, and support.

5. Modes of Communication: Autistic students use different modes of speaking and non-speaking communication as a strategy to improve the clarity of their messages and to minimize feelings of stress and anxiety.

It is noteworthy to mention that one quantitative finding was not identified as a qualitative finding, therefore could not be matched. Specifically, the survey item asking students how excited they would be to see their teacher in the future did not have any corresponding matches with qualitative data. Consequently, this outlying quantitative finding was not included in the main study findings because it was not considered a significant factor impacting autistic students’ school experiences. Data collected from this survey question found over half (56%) of students felt excited to see their teachers again in the future, which may be a comparable to most adolescents nearing the end of their school career. This survey item may be important to consider if a researcher was interested in exploring the relationships between survey items. For example, does a relationship exist between students’ desire to see their teachers again in the future and their current sense of school belonging?
Chapter Summary

This chapter presented a sequential comparative analysis of quantitative data from the online survey (n=72) and qualitative data from the open-ended survey question (n=19), and semi-structured email interview (n=10). Quantitative data were analyzed using descriptive statistics and qualitative data were analyzed using inductive thematic analysis. Quantitative and qualitative data were merged using a joint display technique called the Pillar Integration Process (PIP). The following chapter will discuss each of the study findings in the context of inclusive education practice and policy to create provocations for systemic change.
Chapter 5: Discussion, Conclusion, and Recommendations

Through a critical disability lens, this chapter discusses each of the five study findings in relation to discussion points presented in the literature review and in contrast with studies published since the completion of data collection and data analysis. Following the discussion of findings, conclusions and recommendations for educators and policymakers are offered to encourage the transference of research into action. Lastly, the benefits of the study, ideas for future research, and researcher reflections are discussed.

Teacher Characteristics

Participant accounts of the positive impact “welcoming”, “understanding”, and “respectful” teachers have on their sense of acceptance and belonging is supported by previous research that highlights connections between school context factors, including teacher qualities, and students’ sense of wellbeing in school (Noble & McGrath, 2014). Where student wellbeing is defined as a “sustainable state characterised by predominantly positive feelings and attitude, positive relationships at school, resilience, self-optimism and a high level of satisfaction with learning experiences” (Noble et al. 2008, p.9). Natural and spontaneous teacher actions, including greeting students and inquiring about personal interests, contribute to students’ sense of belonging and helps to improve negative experiences of students with special education needs, who report feeling eight times more excluded than their typical peers (Mitchell & Sutherland, 2020). The simple but significant impact teacher actions have on student wellbeing and belonging is confirmed by autistic students who share that smiling, happy, and friendly teachers make them feel more welcome (Williams, 2007). Initially discussed in the literature review, two meta-synthesis on the self-reported school experiences of autistic secondary students found that
positive teacher qualities also improved student-teacher relationships, which ultimately increased positive domains of student wellbeing (Danker et al., 2016; Dillion et al., 2016).

Contrary to medical and social beliefs on the preferred social experiences of autistic students, having real and relatable teachers that are passionate about teaching are notably important to autistic students. Connecting with teachers personally is, like most students, an experience autistic students value and look forward to. For example, in Saggers et al.’s study, autistic high school students describe teachers who told jokes, performed a magic trick, or shared stories from being in the circus, as “super cool” (p. 178). Using humour and storytelling in the classroom is another naturalistic approach to teaching that engages and motivates students, lowers anxiety, and improves positive interactions between teachers and students (Tosta, 2001). The benefits of teachers who are genuine and passionate about teaching is that it improves student-teacher relationships and enhances students’ overall interest and achievement in school (Croswell & Elliot, 2004).

Autistic student views on the impact teacher characteristics have on their sense of school belonging are noteworthy because they challenge research that maintains that educators do not feel they have the adequate skills to foster inclusion (Loreman, 2014). Treating autistic students in caring, respectful, and personal ways does not require specialized training. However, these fundamental principles of good teaching continue to be overshadowed by historical theories on the presumed abilities, desires, and intelligence of speaking and non-speaking autistic people. This is evident in the zeal many education systems have towards finding treatments and programs to help autistic students fit into “inclusive” settings, rather than systematically exploring ways schools can flex to be more inclusive. While evidence-based practices are necessary to support the unique strengths and needs of autistic students, overlooking the value of
basic principles of humanity is unethical because it contributes to the exclusion and marginalization of autistic students and any other student who is considered non-ordinary. We educators must remind ourselves that the success of inclusive strategies is equally dependent on teacher attitudes and our ability to encourage student learning, as the type or quality of strategy used to support students (Mitchell & Sutherland, 2020).

**Pedagogical Practices**

In the age of personalized learning, also known as differentiation, teachers are expected to continuously adapt their pedagogical practices and modify curricula outcomes to their students’ abilities (Anastasiou et al., 2015). However, research shows that curricular adaptations and modifications are often confused and misused (Humphrey & Lewis, 2008; Lee et al., 2010). This confusion partly stems from similar verbiage and partly from a lack of understanding of how and when each is used. Curricular adaptations pertain to how students learn, and a curricular modification pertains to what students are learning (Alberta Education, 2004; Kurth & Keegan, 2014). Participants shared that it was important to them that teachers provide flexible opportunities for them to participate in class and to demonstrate their understanding of concepts. The short and long-term benefits of consistently using personalized and flexible pedagogical practices are not original concepts for educators, nor are they uniquely helpful for autistic students. Plenty of research exists that highlights the beneficial outcomes of using personalized, strength-based approaches for all students (Hattie & Clarke, 2019). Universal Design for Learning (UDL) is one such approach where educators are challenged to reframe traditional deficit-based thinking and teaching approaches instead of making learning accessible to students by removing barriers (Meyer et al., 2014). For example, by creating multiple entry points for students to access curricula and showcase their knowledge in personally meaningful and diverse
Discussion, Conclusion, and Recommendations

ways. Previous research on the self-reported school experiences of autistic students confirms that personalized and flexible pedagogical practices are essential. However, the visibility of these practices and supports equally matter (Humphrey & Lewis, 2008; Saggers et al., 2011). While autistic students value personalized curricular adaptations and flexible pedagogical practices, they do not want accommodations and support to negatively accentuate their differences. This includes the provision of an education assistant, which is often viewed as the most responsive and effective type of support to give students special education needs. However, research supports that in general education classrooms interactions between autistic students and their teachers and peers are significantly reduced when an education assistant is present (Blatchford et al., 2009; Humphrey & Lewis, 2008; McVittie, 2005; Robertson et al., 2003). While autistic students in this study and previous research value strength-based teaching, it is interesting that of the 23 studies published since 2000 on the self-reported school experiences of autistic students, none concluded that autistic students desired more one-to-one support from an education assistant. This reflection is contrary to educator and parent beliefs on the provision of an education assistant is commonly believed to be the key to successful inclusion. Instead, successful inclusion indicators are more dynamic and complex and must consider strong policy, leadership, resources, teacher education, and accessible curriculum (Brown et al., 2020); Loreman, 2014).

Nearly two-thirds of students in this study reported feeling respected and encouraged by their teachers, which was an overall school experience strength identified by students. This finding is unique and has not been highlighted in previous research discussed in the literature or a recently published meta-synthesis by Williams et al. (2019). However, this discrepancy does not mean that autistic students in other studies feel disrespected or discouraged by their teachers.
Instead, this finding’s uniqueness could be attributed to the mixed-method design of this study, where survey questions relating to teacher respect and encouragement were explicitly included in the study. This notion emphasizes that what we know about autistic students’ school experiences is influenced by research design and the tools we use to gather student perspectives. The limited number of research studies that use a mixed-method design is a limitation highlighted by Fayette and Bond (2018) in their literature review on research methods used to elicit the views of autistic people about their educational experiences; they found that none of the studies adopted a mixed-method approach. However, excluded in their review was Dillon et al. (2016) study that did use a mixed-method design to investigate the school experiences of autistic students in the UK.

**School Environment**

Students shared that school spaces significantly impact their school experiences in both positive and negative ways. School spaces affected students’ engagement in learning, interactions with peers and teachers, personal feelings of wellbeing, and overall sense of school belonging. Students tended to avoid noisy, crowded, and chaotic school spaces and consistently sought out school spaces that helped create feelings of safety, predictability, control, and ultimately personal success. Loud and busy school environments are known to overwhelm autistic students, often causing them to take alternate routes or avoid specific spaces altogether to minimize feelings of stress and anxiety (Humphrey & Lewis, 2008; Kopec, 2012; Saggers, 2015). The long-term adverse effects from repeated exposure to stressful and chaotic environments are highlighted in research that found approximately four in ten autistic students were “being prescribed medication for anxiety as a result of not being able to cope with the school environment” (Marshall & Goodall, 2015, p.3162). The tremendous impact school environments have on autistic students’ learning and wellbeing is supported by several research
studies, including three separate meta-synthesis published by Danker et al. (2016), DePape and Lindsay (2016), and Williams et al. (2019). However, compared to research on evidence-based practices to support autistic students in general education classrooms, research on design standards of classroom spaces is minimal (Martin, 2016). Commonly, classroom organization is dependent on teacher preferences and availability of school resources, which may inadvertently create oppressive and stressful learning environments (Khare & Mullick, 2009). This was evident in two student accounts where they dreaded attending specific classes because the seating arrangements were too close to peers, which caused them to feel “distracted”, “trapped”, and “socially awkward”.

Forty percent of survey participants indicated that they did not feel a sense of school belonging, which is higher than results reported by the Organisation for Economic Co-operation and Development (OECD), where 27% of students across 30 countries indicated that they felt a sense of school belonging (OECD, 2017). Part of this discrepancy might be attributed to the compound impact school environments have on autistic students’ feelings of wellbeing, safety, relationships with peers, and endurance to engage in learning in oppressive environments. As one student shared, “It’s very hard for us to integrate, i feel alienated most of the time”.

Exploring students’ feelings of alienation from a school environment perspective, including physical design, furniture layouts, and timetabling, are worthwhile considerations for researchers, policymakers, and educators. However, in some cases, bottom-up approaches are faster to implement and often more effective. Administrators and teachers can easily invite autistic and non-autistic students to have a voice at the table to co-create inclusive school spaces that support students’ psychosocial wellbeing and academic achievement in ways that do not stigmatize learner difference (McAllister & Maguire, 2012; Jones, 2015).
Peer Relationships

Half of the survey participants shared that they did not feel understood by their peers and one-third of participants did not feel respected by their peers. Research shows that autistic students experience higher levels of social anxiety and rejection when they attempt to conceal their autism in an attempt to be viewed as “normal” (Humphrey & Lewis, 2008; Saggers, 2015). Efforts made by autistic students to camouflage their autistic traits are a result of prolonged exposure to external messages from non-autistic people telling them that it is not normal to be autistic. The harmful effects have led to feelings of rejection, isolation, anxiety, and depression in autistic people (Ashburner et al., 2019; Mehling & Tasse, 2015; O’Hagan & Hebron, 2017; Solomon et al., 2011). Like other adolescents their age, autistic students value peer recognition and acceptance through friendships and shared activities (Daniel & Billingsley, 2010; Deckers et al., 2017; Petrina et al., 2014). However, due to social-communication barriers and autistic mannerisms, autistic youth have fewer friendships inside and outside of school than their non-autistic peers (Taheri et al., 2016; Zeedyk et al., 2014).

As social rules and expectations become more sophisticated with age, autistic high school students also experience more difficulties forming and maintaining friendships (Rotheram-Fuller et al., 2010); which is troubling because having a few quality friendships improve resiliency towards life stresses and reduce feelings of depression and anxiety (Masten et al., 2009). Initially discussed in the literature review, some theorists defend that a weak theory of mind (TofM) partly explains why autistic students have fewer friendships than their non-autistic peers. TofM posits that autistic people lack or have a weakened ability to understand other people’s thoughts and feelings. However, aligning with critical disability theory that confronts ableist ontologies, Milton (2012) defends that the issue is more accurately described as a double empathy problem.
Understanding other people’s thoughts and feelings is a shared responsibility. Therefore, it is unjust to classify one group as having a disability when both groups have difficulty understanding the other. However, the disparity lies in the idea that autistic people need to conform to socially dominant rules to survive and thrive, where non-autistic people do not (Milton, 2012).

**In-School and Cyber Bullying**

One-third of surveyed students shared that they worried about in-school bullying, and one-quarter of students worried about online bullying. Bullying is defined as repeated verbal and aggressive behaviour and intentional social exclusion intended to harm (Hwang, 2017). Cyberbullying is also intended to cause harm through repeated and aggressive measures through electronic communication, such as texts, emails, photos, and videos, including name-calling, cyber-stalking, and humiliating others (Campbell et al., 2013). It is well known that both in-school and cyberbullying incidents are increasing, and autistic students experience more bullying than their peers with no or other special education needs (Symes & Humphrey, 2010). For instance, one study reported that autistic students with no cognitive impairments are four times more likely to get bullied than their typical peers (Little, 2002). In another study based on parent accounts, 65% of autistic children were victimized during the previous year (Carter, 2009).

Positive peer relationships increase autistic students’ sense of in-school safety and belonging (Humphrey & Lewis, 2008, Poon et al., 2014; Saggers, 2015) and are the most effective way to reduce the frequency of bullying (Humphrey & Symes, 2010). While this research found lower reports of bullying than what is found in other research, the discrepancy may be attributed to unexamined context factors such as the size of the school and student population, involvement with positive peer groups, teacher training, and jurisdictional
commitments and policy on the prevention of bullying. Furthermore, similar to general research on the lived experiences of autistic people, autistic self-reports on their experiences related to in-school and cyberbullying are minimal, thus restricting knowledge researchers and educators have to make solid comparisons and to inform policy and effective practice.

**Modes of Communication**

Half of the surveyed students shared that they preferred to communicate by typing, and seven out of ten students who completed the email interview stated that they preferred to type to communicate. The primary reason students preferred to type to communicate was that it helped to minimize their feelings of stress and anxiety when communicating with teachers in front of classmates and peers in social situations. This explanation is not surprising when anxiety is the most common co-occurring condition in autistic youth, with the highest prevalence (4 in 10) being social phobia (Vasa et al., 2015). Having “unreliable speech” (Sparrow, 2017, para 3) is also known to cause stress and anxiety when speaking communication is expected. Unreliable speech is when what is said does not match the intended message, also known as intermittent speech (Sparrow, 2017). Intermittent speech should not be confused with selective mutism; where selective mutism follows a more socially predictable pattern, intermittent speech is influenced by fluctuating factors such as illness, stress, and sensory overload (Sparrow, 2017; Zisk & Dalton, 2019;).

While communication breakdowns were not explicitly identified as an issue by autistic students in this study, the content of messages is also known to influence autistic people’s decisions for using speaking or non-speaking modes of communication. For example, when engaging in dialogue that involves detailed and factual information, an autistic person may be more inclined to use speaking communication. However, if the conversation requires recalling
past experiences or thoughts about the future, autistic people may prefer non-speaking communication (Kim, 2015; Mautistic, 2017). In the anthology titled Typed Words, Loud Voices (Sequenza & Grace, 2015), autistic self-advocate Von Woerkom explains that he uses typing as a strategy to slow the pace of communication to avoid communication breakdowns and to improve the clarity of his messages (Kimmel, 2015). Similarly, autistic author Sparrow (2017) prefers typing communication over speaking communication when feeling stressed from sensory stimulation and unfamiliar situations. Informed by the self-reports of autistic students both within and beyond this study, school jurisdictions must consider the “‘humanness’ of conventionally accepted communication modes” (Douglas et al., 2019, p.10) used in their schools and their subsequent impact on autistic students’ learning and sense of school belonging.

Research on the self-reported school experiences of autistic high school students who type or draw to communicate is extremely minimal. Woodfield & Ashby’s (2016) study is the only one identified throughout this research’s life cycle and is on supporting high school students with autism who type to communicate. Teachers who provide additional space and time for students who type or draw to communicate improve the authentic participation of autistic students and help create a culture of respect in classrooms (Woodfield & Ashby, 2016). Additionally, some autistic students have difficulty with “initiation, thus making timely contributions to academic and social conversations challenging” (2016, p.441). Hence, creating ethical spaces and time for autistic students to use non-speaking modes of communication is crucial to ensuring their voices are included and will help disrupt ableist classroom practices that favour the loudest and fastest student responses (Woodfield & Ashby, 2016).

Autistic students may also use non-speaking modes as a protective measure against social rejection and feelings of failure. For example, accounts of “I am always stumbling over my
words or stuttering” (Alex) highlight that multiple experiences of unreliable speech may lead to fewer social interactions between autistic students and their peers, thus leading to a diminished sense of positive self, based on feelings of frustration and embarrassment. However, as discussed in the Literature Review, augmentative and alternative communication can be both emancipatory and oppressive to disabled people because ableist assumptions are embedded in their use, including socially preferred verbiage and assumptions of cognitive ability and personal agency (Zisk & Dalton, 2019). Educator awareness and understanding of autistic students’ preference for using non-speaking forms of communication is minimal because there is an over-representation of research methods and educational practices that necessitate speaking communication for autistic students to participate (Bond & Fayette, 2018). Furthermore, authorization for students to access assistive technologies may be limited by jurisdictional policies that stipulate conditional access based on medical or speech-language assessments (Zisk & Dalton, 2019). Limiting attitudes and educational practices rooted in deficit models of eligibility fail to recognize the multiple internal and external factors impacting legitimate forms of autistic communication (Baggs, 2012; Kedar, 2018b; Sinclair, 2010).

**Conclusions and Recommendations for Educators and Policy Makers**

Ableist beliefs and expectations are deeply embedded in the structure and practices of education. Consequently, autistic students continue to receive daily implicit and explicit messages telling them to be less autistic and more “normal”. The compound effect of these harmful messages is that students feel rejected, anxious, lonely, and depressed. Based on the views and experiences of autistic high school students, this study offers important insider information for educators and policymakers to consider as they pursue ways to improve the inclusive landscape of their schools structurally, professionally, and pedagogically. Although
minimal in scope, previous research on the self-reported school experiences of high school autistic students supports many of this study’s findings and confirm the bearing teacher mindsets, pedagogical practices, school environments, and peer relationships continue to have on autistic students’ feelings of acceptance, belonging, and academic achievement. Findings from this study suggest that while improvements to inclusive education have been made since the early days of parent advocacy, commitment to removing barriers to increase access to fair and equitable education for speaking and non-speaking autistic students demands attention.

**Inclusive Mindsets**

Predominantly, the inclusive mindsets of teachers are a major factor contributing to the positive and negative school experiences of autistic students. Generally, autistic students feel a greater sense of school belonging when they are welcomed, their strengths and limitations are respected, and they have access to safe school spaces. It is worthy to note that none of the abovementioned characteristics of inclusive mindsets require specialized training or larger budgets, and they are not exclusive to the success of autistic students.

**Balanced Perspectives**

The value of including autistic voice and perspectives in school-based discussions helps educators and students co-create conditions for school success and generate a social world where autistic students can find belonging. Thus, educators and policymakers must seek balanced perspectives in their deliberations because the overrepresentation of outsider viewpoints may overshadow student perspectives and teacher craft knowledge (Conn, 2018; Mitchel & Sutherland, 2020). Craft knowledge is viewed as the skills teachers intuitively develop over time to build strong relationships, including attending to the “personal circumstances, interests, history, and family lives” (Conn, 2018, p. 596) of their students. While creating positive school
experiences for autistic students may start with the small but significant attitudes and actions of educators, the use of more precise pedagogical practices to support autistic students’ academic and social achievements is more nuanced, often requiring specialized training and side-by-side teacher coaching. Consequently, post-secondary teacher preparation programs interested in advancing the field of inclusive education might consider the ways in which their epistemological stances on persons with disabilities trickles down to school experiences of autistic students.

The novelty of this study is its inclusive design and self-representation of perspectives from autistic students who use speaking and non-speaking modes to communicate. To ensure autistic students “can act as experts and advocates on their own communication” (Woodfield & Ashby, 2015, p.447), researchers and educators must commit to creating more enabling conditions for autistic students; which requires adjustment to our over reliance on standardized tests and evidenced-based treatments to guide research, practice, and policy.

Based on autistic high school students’ self-reports, the following recommendations will assist school jurisdictions develop policies and strengthen practices to more ethically and equitably support autistic students. The recommendations are organized into three categories: 1) Pedagogical Practices; 2) Shared Responsibilities; and 3) Systems Support. The impact of the following recommendations is strengthened when educators thoroughly consider them in the context of their dynamic and evolving school ecologies, including infrastructure, resources, student population, staff knowledge and experience, and leadership philosophies.

**Pedagogical Practices**

1. Ensure autistic students are greeted at the beginning of each class. This serves as a natural check-in between teacher and student to enable the identification of any
required accommodations to support the sensory, social, and academic success of
the student.

2. Connect with autistic students by being relatable; including talking about interests,
sharing stories, and using humour.

3. Be organized and knowledgeable about the subject matter and passionate about
teaching.

4. Provide clear course outlines and timelines for assignments, presentations, and
exams.

5. Provide flexible opportunities for autistic students to showcase their knowledge and
interests in personally meaningful ways.

6. Include autistic students in the identification of curricular adaptations and
modifications. Clearly communicate impact, if any, on assessments and grades.

7. Set regular in-person or virtual meetings with autistic students to support the
development of their self-advocacy skills, to celebrate achievements, and to
collaboratively respond to concerns and questions.

**Shared Responsibilities**

1. Provide alternate times and routes for student transitions between classes.

2. Provide alternative spaces and times for autistic students to eat lunch and take
breaks.

3. Allow autistic students to wear sunglasses and hats to block artificial lights, and
noise-cancelling headphones to reduce auditory stimuli.
4. To promote psychological and physical feelings of safety, provide autistic students non-contingent access to low arousal spaces that are easily accessible and non-stigmatizing.

5. Co-identify classroom seating options that respect autistic students’ sensory, social, and communicative preferences.

6. Provide flexible opportunities for autistic students to select their preferred mode of speaking and non-speaking communication.

7. Consider the impact of sensory, social, and academic factors on autistic students’ preferences for the single or interchangeable use of speaking and non-speaking modes of communication.

8. Provide equitable classroom participation opportunities by giving autistic students additional time to process and respond to information.

9. Ensure autistic students have access to multi-disciplinary specialized supports, including speech-language pathologists, occupational therapists, physiotherapists, psychologists, resource teachers, and school counsellors.

10. Knowing that peer support is the most robust defence against bullying, imbed mentorship and leadership opportunities into school-wide practices to support the development of positive peer networks and interdependence between diverse groups of students.

11. Conduct regular school-wide celebrations of positive and inclusive attitudes and actions of all students and staff.

*Systems Support*
1. Consider ways in which standardized and non-standardized assessments perpetuate normative expectations of speaking voice as rational voice and how this may lead to inaccurate assumptions of cognitive and academic ability of autistic students.

2. Support autistic students’ right for freedom of expression (CRC, 2006) by providing access to non-stigmatizing alternative modes of non-speaking communication, including assistive technologies, art, and music.

3. Support autistic students right to self-select the least restrictive modes of communication (CRC, 2006) by removing barriers to self-advocacy, including policies that require autistic students to provide medical letters, psycho-educational assessments, speech-language assessments, and occupational therapy assessments to receive curricular adaptations and modifications and access assistive technologies.

4. Provide flexible options for learning, including online and in-person learning spaces.

5. Ensure anti-bullying policies adequately support students with disabilities and clearly outlines proactive and protective measures that do not “blame the victim”.

6. Include perspectives of persons with disabilities in school design, policy development, and school improvement planning.

**Benefits of the Research and Considerations for Future Research**

**Benefits of the Research**

Since my original review of literature on the self-reported school experiences of autistic students, a new meta-synthesis was published, titled “How pupils on the Autism Spectrum make sense of themselves in the context of their experiences in a mainstream school setting: A
qualitative meta-synthesis” (Williams, et al., 2019). The meta-analysis presents similar themes found in this research study, specifically related to the importance of autistic students developing relationships with teachers and peers, and the impact of school environments. However, compared to the numerous articles examining the phenomena, the authors of this meta-synthesis insightfully point out that each of the 17 reviewed studies represented “the voice of verbally and cognitively able, male pupils in mainstream secondary schools in Western societies” (Williams et al., 2019, p.11). The disproportionate representation of speaking voice in autism research continues to be problematic and can be attributed to the researcher’s beliefs on legitimate forms of knowledge and ableist methods used in research (Fayette & Bond, 2017).

Based on “actually autistic” (Craine, 2020, p. 263) experiences, this study sought to better understand the school experiences of autistic high school students and improve ableist research practices used to include autistic students in research. Thus, the benefits of this research are that it:

a) Improves educator understanding of autistic students’ school experiences.

b) Highlights priorities for school-based and jurisdictional reform to improve the educational experiences of autistic students.

c) Informs policy revisions and future development.

d) Informs professional development topics and the identification of resources to support autistic students.

e) Assists colleges and universities develop teacher preparation programs that strengthen beginning teachers’ knowledge and ability to support autistic students.

f) Signals to the autistic community that they are valued, and their perspectives matter in research and education.
g) Advances literature on the self-reported school experiences of autistic students attending schools in Canada; and

h) Provides a methodological example to fellow researchers on ways to create ethical research spaces that improve the inclusion of speaking and non-speaking autistic voice in research.

**Considerations for Future Research**

I have framed my considerations for future research as questions. These questions can be used to guide future research on autistic first voice experience. These considerations are offered based on my experiences as an educator and a researcher. Item six is based on Pellicano et al.’s (2014) study, which highlighted research priorities articulated by the UK autism community. I believe that this item is relevant to educators and practitioners in the field of inclusive education in Canada. The considerations and questions for future research are:

1. What relationship exists between the physical environment assessments are completed in and diagnostic outcomes for autistic students?

2. What opportunities exist for autistic students to use diverse modes of speaking and non-speaking communication to complete standardized and non-standardized assessments?

3. If autistic students were to design a school, what would it look like?

4. In what ways can teachers and autistic students co-create micro spaces within macro school spaces?

5. How can school communities adopt “nothing about us, without us” practices to improve the inclusive education experiences of autistic students?
6. How best do autistic students learn in inclusive settings and are their differences between elementary, middle, and high school settings? (Pellicano et al., 2014).

Limitations and Delimitations

Based on reflection throughout the research lifecycle, including the process of receiving ethical approval and engagement with participants during data collection, there are several limitations to this study. First, while an autistic colleague reviewed the research proposal, an autistic person did not review the data or the discussion of findings. Having the perspective of an autistic person as collaborator during the analysis of data would help to minimize ableist interpretations of autistic experiences and would enrich the discussion of findings. Second, not all participants received the same compensation for participating in the research. Participants in Phase 1 and Phase 2 did not receive two dollars compensation for completing the survey and only participants in Phase 2, and Phase 3 received a twenty-five-dollar Amazon eGift card for completing the online email interview. Third, while the 30-minute email interview seemed like a reasonable amount of time to interact with participants, an option to complete the email interview asynchronously may have provided participants more space and time to reflect on their school experiences and type their responses. Fourth, while most participants preferred non-speaking modes of communication, an option for participants to interview via phone call or Skype may have been beneficial. Fifth, increased representation of participants outside of Ontario, British Columbia, and Alberta, may have improved researcher and educator understanding of student experiences across Canada. Lastly, the sample size was small and non-randomized and there was an English only version of the study.

Delimitations of the study are: proof of diagnosis; IQ Scores; identification of co-occurring diagnoses such as attention deficit hyperactivity disorder (ADHD) or anxiety; the number of
years in high school; attendance rates; family context; access to community supports such as speech-language therapy; access to school supports and resources; teacher training and experience; inclusive school policies; building size; and total school population.

**Researcher Reflections**

As I reflect on this research study from inception to now, I am left with two thoughts. The first thought challenges my ableist assumptions on autistic people’s abilities, including their supposed lack of self and social awareness, and second, the treatment of disabled people during the COVID-19 pandemic.

The more I immerse myself in the narratives of speaking and non-speaking autistic people, including autistic academics, bloggers, novelists, political activists, the more conscious I have become to how deeply aware autistic people are on the historical and current medical, social, and political injustices against their community and the ensuing effects. While I hesitate to share this thought because it is noticeably ableist, it is important to talk about because it indicates that the autistic community’s massive efforts to reclaim their voice are working and positively impacting social change. Personally, and professionally I am much more aware of loud voices, token voices, and missing voices at the table and how particular narratives are used to defend positions of power. I am also more aware of how knowledge construction is influenced by both what is said and what is left unsaid and that researchers and educators need to engage in more ethical practices ensuring diverse and opposing voices are equally included. Ethical practices, such as providing accessible opportunities for self-representation of non and minimally speaking autistic voice, help to re-balance power dynamics that have led to the pathologisation of autism. Researchers, educators, and autism allies need to find ways to mobilize inclusive practices (Kapp, 2020) to relieve the massive pressure on the autistic community to “solve problems [and
injustices] they did not create” (p.10). As Sinclair (1993) states, “We need you. We need your help and your understanding. Your world is not very open to us, and we would not make it without your strong support” (para.17).

Ironically, this leads me to our current reality, the COVID-19 pandemic. In response to people’s unfamiliar feelings of loneliness, isolation, and fear during the current pandemic, autistic Maxfield Sparrow offers words of encouragement to autistic comrades in their blog post titled “Autistic in the pandemic: A call to action” (March 19, 2020). Sparrow encourages autistic people to resist the temptation to jest about non-autistics having to social-distance, self-isolate, and feel the impacts of social exclusion. Instead, Sparrow states with pride that “it’s time to own [that we have spent our entire lives preparing for social distancing] and talk about our possible roles in this historic time” (para. 2). Sparrow goes on to say:

Be patient with them - coping with being alone is a skill like any other. We have had more chances to practice it, just as people with majority neurotypes have had more chances than us to practice socialization. Now we are the experts, and they are the ones who are deficient in a needed skill. We can help them, and we can do it with more kindness and compassion than many of us experienced at the hands of “helping” professionals in the past. So many of us are experts at loving without touching.

I am taken aback by the irony and humbled by the grace and undeserved kind-heartedness offered by Sparrow and others in the autistic community who offer words of reassurance including its “okay not to be okay” (den Houting, 2020, p.2) towards a society that historically, and currently, only offers mistreatment and marginalization. It is clear; we need all types of people.
Conclusion

This study addresses a gap in the literature on the self-reported school experiences of speaking and non-speaking autistic high school students within a Canadian context. Overall, autistic students report that their high school experiences are mediocre at best and that Canadian inclusive practices and policies need improvement. These findings contribute to researcher and educator understanding of the underlying features contributing to autistic students’ experiences and offer recommendations to educators and policymakers to improve their schools’ inclusive landscape and the academic and wellbeing outcomes of autistic students. While improvements could be made to the inclusive design of this research, it offers a promising example to fellow researchers and educators to investigate ways to improve the inclusion of minimally or non-speaking and speaking autistic voices in their work. Further research that supports the use of multiple modes of speaking and non-speaking communication is strongly warranted and will continue to disrupt power differentials between disabled and non-disabled people and ableist standards and practices used in research and education.
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Appendix A: Timeline of European and Western Historical Perspectives

<table>
<thead>
<tr>
<th>Researchers</th>
<th>Parent-Researchers</th>
</tr>
</thead>
</table>
| 1200-1700 | • St. Francis of Assisi & Brother Juniper  
|            | • Jean Marc Itard & Victor |
| 1910       | • Eugen Bleuler-autism “autos” for self |
| 1938-1944 | • Hans Asperger-high functioning autism  
|            | • Leo Kanner-Infantile autism with psychobiological origins, including parental causation |
| 1950’s    | • Bruno Bettelheim- “refrigerator mother”  
|            | • DSM-I: Autism as a subtype of schizophrenia |
| 1960’s    | • Ivar Lovaas-Lovaas Method (ABA)  
|            | • DSM-II: Autism as a subtype of schizophrenia  
|            | • Prevalence 4.5/10000 (1966) |
| 1970’s    | Bernard Rimland-Autism Society of America & Autism Research Institute  
|            | Ruth Sullivan-Autism Society of America & IDEA |
| 1980’s    | Lorna Wing-National Autistic Society (UK), introduced Asperger’s Syndrome  
|            | Eric Schopler- TEACCH |
|            | • Andrew Wakefield-MMR vaccine causing autism  
|            | • DSM-IV: Asperger/ PDD added  
|            | • Prevalence 15/10000 |
| 2000’s    | • Prevalence 1/150 (2007)  
|            | • Prevalence 1/110 (2009)  
|            | • Prevalence 1/88 (2012)  
|            | • Prevalence 1/54 (2019) |
Appendix B: Research Pathway

Research Design

• Critical disabilities theoretical framework and a phenomenologically informed research lens.
• Mixed method convergent parallel design to collect quantitative and qualitative student perception data using synchronous and asynchronous methods.

Recruitment

• Snowball sampling through provincial and territory autism organizations, including their social media platforms (Twitter, Facebook); Convenience Sampling using Amazon’s MTurk.
• Introductory email sent with a sharable infographic provided with a direct link to survey and consent information.
• Canadian residents, minimum of 1 year of high school, 15-21 yrs, ASC, AS, PDD-NOS
• If consent is not given and/or eligibility criteria is not met in the 5 demographic questions, survey ends.

Consent & Ascent

• Participants considered mature minors, possessing the decision-making capacity to consent or decline participation in the study.
• Participant information documents about the research, participation, risk, confidentiality and consent available for download. Parent information about the study also available.
• Ascent collected at the beginning of the survey and before/during the email interview. Participants will be informed that they can take breaks or end participation at any time prior to final submission of both the survey and interview portion of the study.

Data Collection

• QUAN (n=72): Asynchronous survey open for 12 weeks using Qualtrics. Survey included 6 demographic questions; 18 Likert scale questions to collect student perception data based on 6 education themes; and 1 open-ended question should the participant want to share additional information related to their school experiences.
• QUAL (n=10): Participants voluntarily provided email address to participate in a 30-minute synchronous semi-structured email interview.

Data Analysis

• QUAN: Descriptive statistical analysis reporting on the mean and SD of student responses related to the above 6 themes.
• Data Integration: QUAN and QUAL data sets were integrated using the Pillar of Integration Process (PIP) and thus were used to answer the research question.

Data Verification

• Credibility through triangulation (survey data, interview data, previous research).
• Transferability by comparing QUAN and QUAL data to previous research on the self-reported school experiences of autistic students.
• Confirmability achieved by providing an audit trail of data collection, analysis and interpretation of the data.
• Dependability of data collection achieved by sharing the processes of data collection, analysis, and results with an external autistic researcher and interested autism agencies.
Appendix C: Online Survey

Link to Qualtrics:  https://survey.ucalgary.ca/jfe/form/SV_eVR24FIfRTD6rpr

*The formatting of the below PDF copy of Survey is set by Qualtrics.

Directions

Welcome to the study titled:
What are the self-reported high school experiences of speaking and non-speaking autistic students in Canada?

Before the survey begins, you will need to read about the study to give informed consent to participate.

Parent Information

Participant Information

Now that you have carefully read the information on providing consent, please answer the following: if you have further questions, please email:
chandra.lebenhagen@ucalgary.ca

- I have read and understand the participant information booklet.
- I understand the benefits and risks involved in being part of this study.
- I understand that I have the right to withdraw from this study at any time prior to final submission of the survey.
- I agree that once I submit my answers the information I provide can be used for research purposes.
- Yes, I consent to participating in this study.
- No, I do not wish to participate in this study.

There are a total of 25 questions.

Please answer questions as best you can.
If you feel tired you can take as many breaks as you like.

Introduction

I identify with the following:

- Autism Spectrum Condition
- Asperger's Syndrome
- Pervasive Developmental Disorder
- I prefer not to answer

I prefer to communicate by:

- Speaking
- Typing
- Other

I identify as being:
I am between the age of 16 and 21 and have completed grade:

- Female
- Male
- You don’t have an option that applies to me. I identify as:
  
- I prefer not to answer

The province or territory I live in is:

- British Columbia
- Alberta
- Saskatchewan
- Manitoba
- Ontario
- Quebec
- New Brunswick
- Nova Scotia
- Prince Edward Island
Pedagogical Effectiveness

How often do you receive feedback at school?

- Almost never
- Once in a while
- Often

Pedagogical Effectiveness

How comfortable are you asking questions?

- Not comfortable
- Slightly comfortable
- Somewhat comfortable
- Quite comfortable
- Extremely comfortable
- I prefer not to answer

Pedagogical Effectiveness

- Newfoundland and Labrador
- Nunavut
- Northwest Territories
- Yukon
- I live outside of Canada
Pedagogical Effectiveness

How interesting is school?

- Not at all interesting
- Slightly interesting
- Mostly interesting
- Very interesting
- I prefer not to answer

School Climate

How fair or unfair are the rules at school?

- Very unfair
- Slightly unfair
- Neither fair or unfair
- Slightly fair
- Very fair
- I prefer not to answer

School Climate

How pleasant or unpleasant is the physical space at your school?
School Climate

How positive or negative is the energy at school?

- Very unpleasant
- Somewhat unpleasant
- Neither pleasant or unpleasant
- Somewhat pleasant
- Very pleasant
- I prefer not to answer

School Engagement

How excited are you to go to school?

- Very negative
- Somewhat negative
- Neither negative or positive
- Somewhat positive
- Very positive
- I prefer not to answer
School Engagement

How eager are you to participate in your classes?

- Not excited
- Slightly excited
- Quite excited
- Extremely excited
- I prefer not to answer

School Engagement

How often do your teachers take time to ensure you understand the material?

- Not at all eager
- Slightly eager
- Quite eager
- Extremely eager
- I prefer not to answer
School Engagement

Overall, how high are your teachers’ expectations of you?

- Almost never
- Once in awhile
- Frequently
- Almost always
- I prefer not to answer

Student-Teacher Relationships

- Not very high
- Somewhat high
- Quite high
- Extremely high
- I prefer not to answer
How many of your teachers are respectful towards you?

- None of my teachers
- Some of my teachers
- Most of my teachers
- All of my teachers
- I prefer not to answer

Student-Teacher Relationships

How much do your teachers encourage you to do your best?

- Almost never
- Once in a while
- Frequently
- Almost always
- I prefer not to answer

Student-Teacher Relationships

How many of your teachers would you be excited to see again in the future?
School Belonging

How well do peers at your school understand you as a person?

- None of my teachers
- Some of my teachers
- Most of my teachers
- All of my teachers
- I prefer not to answer

School Belonging

How much respect do peers in your school show you?

- Do not understand me
- Understand me a little
- Understand me quite a bit
- Completely understand me
- I prefer not to answer
School Belonging

Overall, how much do you feel like you belong at your school?

- No respect
- A little respect
- Quite a bit of respect
- A lot of respect
- I prefer not to answer

School Safety

How often do you worry about bullying at school?

- Almost never
School Safety

How often do you worry about online bullying?

- Once in awhile
- Frequently
- Almost always
- I prefer not to answer

Comments

Is there anything else you would like to share about your experiences at school?
Supports

Did you receive support in order to complete this survey?

☐ Yes
☐ No

Draw

Thank you for your participation! If you are interested in entering your email to enter a draw for a $50 Amazon Gift Card, please provide your email address below. This is completely voluntary and will be kept confidential.

☐ Yes, my email contact is:
☐ No thank-you
Appendix D: Semi-Structured Email Interview Questions

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>Follow-up Interview Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How often do you receive feedback at school?</td>
<td>What type of teacher feedback is the most meaningful to you?</td>
</tr>
<tr>
<td>2. How comfortable are you asking questions?</td>
<td>What can teachers do to help you feel comfortable when you need to ask them a question?</td>
</tr>
<tr>
<td>3. How interesting is school?</td>
<td>What interests you the most at school?</td>
</tr>
<tr>
<td>4. How fair or unfair are the rules at school?</td>
<td>What school rules do you think are fair and unfair?</td>
</tr>
<tr>
<td>5. How pleasant or unpleasant is the physical space at your school?</td>
<td>What school spaces are the most calming to you?</td>
</tr>
<tr>
<td>6. How positive or negative is the energy at school?</td>
<td>Describe one improvement your school could make in order to make if feel more positive?</td>
</tr>
<tr>
<td>7. How excited are you to go to school?</td>
<td>If you could imagine a perfect school day, what would it be?</td>
</tr>
<tr>
<td>8. How eager are you to participate in your classes?</td>
<td>What is your most preferred way to participate in class?</td>
</tr>
<tr>
<td>9. How often do your teachers take time to ensure you understand the material?</td>
<td>What is your most preferred way to interact with teachers?</td>
</tr>
<tr>
<td>10. Overall, how high are your teachers’ expectations of you?</td>
<td>Share an example of how you like to be challenged in school?</td>
</tr>
<tr>
<td>11. How many of your teachers are respectful towards you?</td>
<td>What can teachers do to make you feel respected?</td>
</tr>
<tr>
<td>12. How much do your teachers encourage you to do your best?</td>
<td>How do you like to be encouraged to do your best at school?</td>
</tr>
<tr>
<td>13. How many of your teachers would you be excited to see again in the future?</td>
<td>In your opinion, what are the characteristics of a great teacher?</td>
</tr>
<tr>
<td>14. How well do peers at your school understand you as a person?</td>
<td>What type of activities do you like to do with peers at school?</td>
</tr>
<tr>
<td>15. How much respect do peers in your school show you?</td>
<td>Describe a time where you felt a peer at school showed you respect.</td>
</tr>
<tr>
<td>16. Overall, how much do you feel like you belong at your school?</td>
<td>What makes you feel like you are part of a school community?</td>
</tr>
<tr>
<td>17. How often do you worry about bullying at school?</td>
<td>Due to the potentially sensitive nature of these 2 questions, no follow-up semi-structured interview questions will be asked relating to the topic of bullying.</td>
</tr>
<tr>
<td>18. How often do you worry about online bullying?</td>
<td></td>
</tr>
</tbody>
</table>

Due to the potentially sensitive nature of these 2 questions, no follow-up semi-structured interview questions will be asked relating to the topic of bullying.
Appendix E: Introduction Letter

Date:

Dear X:

My name is Chandra Lebenhagen and I am a doctoral student at the University of Calgary. I am requesting your assistance in sharing information regarding an online titled:

**What are the self-reported school experiences of speaking and non-speaking high school students in Canada?**

**Summary of the Research:**
This study seeks to explore the self-reported inclusive educational experiences of speaking and non-speaking autistic high school students in Canada. As such, this research will fill a gap in research and understanding on the self-reported experiences of autistic youth in Canadian schools and will help to inform inclusive education policy and practice in school jurisdictions. Autistic students will have the opportunity to share their unique perspectives through the use of an online survey, and if they wish, participate in an email interview. The online design of the research provides flexible opportunities for autistic participants to receive and share information.

**Researchers:**
Gabriela Alonso-Yanez (Supervisor)
Chandra Lebenhagen (Student)

**Who Can Participate?**
Eligible participants must:
- Self-report having a diagnosis of Autism Spectrum Condition, Asperger’s Syndrome or Pervasive Developmental Disorder-Not Otherwise Specified.
- Are between the ages of 15 and 21 years old.
- Have completed at least one year of high school in an inclusive setting in Canada.
- Speaking or non-speaking and have access to technology including a smartphone, tablet or a computer and the internet.

**What’s Involved?**
- Participants will be asked to answer 24 survey questions and 1-open ended response.
- Following completion of the survey, participants will be invited to voluntarily provide their email address should they be interested in participating in a semi-structured email interview which will be based on their survey responses.
- Participants will be able to receive personalized support to answer the questions and can respond to questions at a time that is most convenient to them.
- Anticipated time to complete the survey is 10-15 minutes and 30 minutes for the interview.
- Participation in the survey and follow-up interview is completely optional. Participants may decline to answer any questions that they do not feel comfortable answering and can end participation in the study at any time prior to final submission.
- Participants’ choice to participate in the research or not, will not affect the services they get from any of the agencies which are doing the recruitment.

**How will participants be compensated for their participation?**
Participants can voluntarily provide their email to enter to win a $50 Amazon Gift Card.
What’s the deadline to participate?
Survey will be open until November 30, 2019

Contact Information:
Chandra.lebenhagen@uclagary.ca

Ethics Approval Number:
The University of Calgary Conjoint Faculties Research Ethics Board has approved this study (REB19-0185)

Below you will find a direct link to the study, that can be shared with autistic students in your community. At the beginning of the survey there are resources for students and parents that includes detailed information about me, the study, eligibility and participation requirements.

[Direct link]

Education Experiences of Autistic High School Students in Canada
https://survey.ucalgary.ca/jfe/form/SV_eVR24FffRTD6rpr
The University of Calgary Conjoint Faculties Research Ethics Board has approved this study
REB19-0185

Should you require further information or wish to speak to me personally, please feel free to contact me at any of the following:

Name of Researcher: Chandra Lebenhagen
Faculty Department: Werklund School of Education, University of Calgary
Email: Chandra.lebenhagen@ucalgary.ca
Sponsor: None

Kind Regards,

Chandra Lebenhagen
Appendix F: Parent Information

Dear Parent/Guardian:

My name is Chandra Lebenhagen and I am a doctoral student at the University of Calgary. I am conducting research that aims to gather information on the self-reported experiences of Canadian students attending high school in inclusive settings. Below you will find brief information on my background and connection to the research, the importance of the research, participation requirements, and benefits and risks to participation. Should you require further information or wish to speak to me personally, please feel free to contact me at any of the following:

Name of Researcher: Chandra Lebenhagen  
Faculty Department: Werklund School of Education, University of Calgary  
Telephone & Email: 403-703-4159 / Chandra.lebenhagen@ucalgary.ca  
Study Title: What are the self-reported school experiences of speaking and non-speaking autistic high school students in Canada?  
Sponsor: None  
Approval: The University of Calgary Conjoint Faculties Research Ethics Board has approved this study (REB19-0185).

Personal and Professional Connection to the Research:  
For twenty years I have personal and professional connections to autistic individuals, their families and the study of ethical best practices. I have personal family connections as well as long standing relationships with former students and their families. Professionally, I have been a special education educator in both private and public education settings, specifically supporting autistic students from 3-21 years of age. Conducting research that centers on the personal voices and experiences of autistic students is important to me personally and as a committed educator and autism ally.

Background Information for the Study:  
- While the inclusion of autistic voice in research is improving, insufficient research exists that includes the self-reported experiences and perspectives of autistic individuals.  
- This study seeks to explore the self-reported inclusive educational experiences of autistic high school students in a Canadian context.

Why is this research important?  
- To increase understanding of autistic students’ high school experiences.  
- To provide opportunity for speaking and non-speaking autistic individuals to share their experiences and knowledge.

Who can join this study?  
- Students who self-reports as having a diagnosis of Autism Spectrum Disorder, Asperger’s Syndrome or PDD-NOS.  
- Students between the ages of 15 and 21 years old.  
- Students who have completed at least one year of high school in an inclusive setting in Canada.  
- Participants may be speaking or non-speaking and must have access to technology including a computer, tablet or smartphone and the internet

What will happen during the study?  
- Participants will be asked to answer 24 survey questions and 1-open ended response.
Following completion of the survey, participants will be invited to voluntarily provide their email address, should they be interested in participating in a semi-structured email interview, which will be based on their survey responses.

- Participants will be able to receive personalized support to answer the questions and can respond to questions at a time that is most convenient to them.
- Anticipated time to complete the survey is 10-15 minutes and 30- minutes for the open-ended questions.
- Participation in the survey and email questions is completely optional. Participants may decline to answer any questions that they do not feel comfortable answering and can end participation in the study at any time prior to final submission.
- Participants may voluntarily provide their email address to enter a draw for a voluntary $50 Amazon Gift Card.

**What are the benefits of this study?**

- This research will provide opportunity for autistic students to self-report their school experiences.
- Results of this research will:
  - Give opportunity for autistic students to share their authentic experiences.
  - Help inform best practice for educators, researchers, and policy makers.

**What are the risks of this study?**

- Some questions may be upsetting. Your child can decline to answer any of the questions they do not feel comfortable answering. If your child feels upset resources will be provided at the end of the survey.
- This study will have no bearing on your child’s relationship with their school or teachers.
- Participants’ choice to participate in the research or not, will not affect the services they get from any of the agencies which are doing the recruitment.
- Your child may feel tired after answering questions.
- If your child feels extremely upset, please contact Crisis Text Line at: https://www.crisistextline.org.

**Will privacy be protected?**

- Research data collected for the survey portion will not include any identifying information such as your child’s name, date of birth, address or school.
- If your child decided that they are interested in answering 2-follow-up email questions, they will be required to share their email address. Email addresses and any identifying information will be anonymized.
- Survey responses and email responses will be stored on secure, password-protected servers at the University of Calgary. Only researchers at the University of Calgary will have access to the survey responses.
- All data will be kept for five years following initial publication of the results and then be destroyed. Any future use of this research data is required to undergo review by a Research Ethics Board.
- Research findings may be published and/or presented at conferences.

**Can I withdraw from the study?**

- Participants are free to exit the survey and email portion of the research any time prior to final submission. If a participant chooses not to respond to the email questions after providing their email contact, their email will be destroyed within 1-month of the survey closing.
Consent to Participate in the Study:
- Participants who want to participate in the study will select the boxes that indicate that they have read and understand the information provided in the participant consent booklet. The survey will close for participants who do not consent.

Questions/Concerns
If you or your child have questions or concerns, at any time prior, during or after the study please contact: Chandra Lebenhagen at: Chandra.lebenhagen@ucalgary.ca
Appendix G: Student Information Booklet

Information for Student Participants

Thank-you for your interest in participating in research! In a question and answer format, you will find information about this research study that will help you decide if you would like to join! After reading this booklet, you will be able to return to the online survey to tell us if you would like to join the study.

Research Question:

What are the self-reported school experiences of autistic high school students in Canada?
What is research?

Research is a way to learn more about certain topics and human experiences. There are many types of research, including experimental research that may be done in a lab or participatory research that includes views and ideas from everyday people.
What new information is this study looking for?

This research is looking to learn about the inclusive education experiences from the perspective of speaking and non-speaking autistic high school students in Canada.
Who is the researcher?

My name is Chandra Lebenhagen and I live in Calgary, Alberta with my family and dog named Theodore. I am a teacher, but mostly work as a learning specialist where I work with other educators to improve educational experiences for autistic students. I have personal and working relationships with autistic individuals for over 20 years.
Why am I interested in learning about your school experiences?

Listening to and learning from autistic student’s perspectives on their school experiences is important. It helps educators and students work as a team to better understand what works well and what areas need to be improved.
Why is this research important?

1. Autistic student voice is important, whether you are speaking or non-speaking!
2. Your perspectives need to be included in discussions about schooling!
3. There is little research that includes the perspectives of Canadian high school students that are autistic!
Who can join this study?

1. You have a diagnosis of autism, Asperger’s, or PDD-NOS.
2. Are between 15 and 21 years old.
3. Have completed at least one year of high school in an inclusive setting in Canada.
4. Have access to a computer, tablet, or a smartphone and the internet.
How do you join this study?

If you answer ‘yes’ to all of the criteria in the section “Who can join this study?” and understand the information provided in this booklet, you can give your consent to participate in this study at the beginning of the online survey. If you consent, the survey will begin. If you don’t consent, the survey will end.
What will happen during the study?

1. You will be asked to answer 24 questions using a Likert Scale. Which means you “click” on the box that most closely answers the question that represents your experiences at school.
2. After you have completed the 24 questions, there is a space where you can provide additional information if you choose.
3. You will also be asked if you would like to participate in a follow-up 30-minute semi-structured email interview, which will be based on your survey responses. If you agree, you will voluntarily provide your email address to receive the questions. If you do not agree, the survey will end. Participants who chose to participate in the semi-structured email interview will receive a $25 Amazon e-Gift Card.
4. If you would like help completing the questions, you are able to ask for familiar support. This might mean someone reads the question to you, scribes your answer, or “clicks” the box for you.
How long will it take to complete the questionnaire?

1. Everyone works at their own pace. Answering the survey questions may take between 10-15 minutes and participating in the semi-structured email interview may take 30-minutes.
2. You are free to answer the questions at a time that works best for you. You may decide to take short or long breaks in between answering the questions.
What are the risks to joining the study?

- Some questions may be upsetting. You can decline to answer any of the questions that you do not feel comfortable answering. If you feel upset, you can access resources provided at the end of the survey.
- You will be able to respond to the questions in your own space, at your own time and with support if required.
- Participation in this study is anonymous and will have no impact on your relationship with your school or teachers.
- Participants’ choice to participate in the research or not, will not affect the services they get from any of the agencies which are doing the recruitment.
- If you decide to participate in the semi-structured email interview, you will be required to provide your email address in order to participate.
- You may feel tired or stress if you recall an unpleasant memory. However, please remember that you can take as many breaks as you like, not answer the question, or end your participation at any time. If you feel extremely upset, you can contact the Crisis Text Line at: https://www.crisistextline.org.