Actually Autistic at School: Giving Voice to #ActuallyAutistic Perspectives on School Inclusion

Natalie Lawy

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Abstract

Autistic students are at risk for poor outcomes at school (Adams, 2022; Ashburner et al., 2010; McDougal et al., 2020; Munkhaugen et al., 2019; Totsika et al., 2020), and teachers in Nova Scotia feel they lack the training and tools to adequately support autistic students in their classrooms (Corkum et al., 2014). Autistic students feel the same way, identifying school staff's poor understanding of autism as a significant barrier to their inclusion and participation (Ducarre, 2023). Very little data has been collected directly from autistic students in Canada about their school experiences and no data has been collected in Nova Scotia to date. The present study, conducted by an autistic researcher, uses semi-structured interviews incorporating novel interview methodology to support inclusion and accessibility for autistic participants. Reflexive thematic analysis is used to identify how autistic students describe their experience of inclusion at school. Key findings signal the significance of interpersonal relationships, the role of personal interests in relationships and academic success, and identification of specific communication gaps between teachers and autistic students. Recommendations for further research include the creation of a professional development workshop for educators to promote improved communication between educators and autistic students. The communication gaps identified in the present study present specific, high-impact targets for teacher training to effect meaningful change in our schools.

Résumé

Les élèves autistes risquent d'obtenir de mauvais résultats à l'école (Adams, 2022 ; Ashburner et al., 2010 ; McDougal et al., 2020 ; Munkhaugen et al., 2019 ; Totsika et al., 2020), et les enseignants de Nouvelle-Écosse estiment qu'ils n'ont pas la formation et les outils nécessaires pour soutenir efficacement les élèves autistes dans leurs classes (Corkum et al., 2014). Les élèves autistes sont du même avis et considèrent que la mauvaise compréhension

de l'autisme par le personnel scolaire est un obstacle important à leur inclusion et à leur participation (Ducarre, 2023). Très peu de données ont été recueillies directement auprès d'élèves autistes au Canada sur leurs expériences scolaires, et aucune donnée n'a été recueillie en Nouvelle-Écosse à ce jour. La présente étude, menée par une chercheuse autiste, utilise des entrevues semi-structurées qui intègrent une nouvelle méthode d'entrevue pour favoriser l'inclusion et l'accessibilité des participants autistes. L'analyse thématique réflexive est utilisée pour identifier la façon dont les étudiants autistes décrivent leur expérience de l'inclusion à l'école. Les principales conclusions signalent l'importance des relations interpersonnelles, le rôle des intérêts personnels dans les relations et la réussite scolaire, et l'identification de lacunes spécifiques dans la communication entre les enseignants et les élèves autistes. Les recommandations pour la suite de la recherche comprennent la création d'un atelier de développement professionnel pour les éducateurs afin de renforcer la communication entre les éducateurs et les élèves autistes. Les manques en matière de communication identifiés dans la présente étude présentent des objectifs spécifiques et importants pour la formation des enseignants afin d'apporter des changements significatifs dans nos écoles.

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Autistic children are not thriving to their full potential in our schools, either academically (McDougal et al., 2020; Totsika et al., 2020) or socially (Adams, 2022; Ashburner et al., 2010; Munkhaugen et al., 2019). This thesis begins with a review of our present understanding of autistic students' performance and inclusion at school, current support practices in Nova Scotia, and the limitations of the existing research base. First-voice research asking autistic people about their school experiences is limited, and the present study addresses the gap in our knowledge about the experience and perceptions of autistic students in Nova Scotia regarding school inclusion.

A Note on Language and Identity

This paper strives to use language that is both accurate and respectful of the autistic community. First and foremost is the use of identity-first language (autistic person) instead of person-first language (person with autism). Identity-first language is preferred by a majority of autistic people (Bonello, 2022; Bury et al., 2023; Kapp et al., 2013; Keating et al., 2023; Kenny et al., 2016; Shakes & Cashin, 2020) and supported by the American Psychological Association (American Psychological Association, 2021; Dunn & Andrews, 2015). Choice of language is important, as it has the power to either perpetuate or reduce stigmatization and exclusion of autistic people (Bottema-Beutel et al., 2021). Several important terms which may be unfamiliar to some readers are defined in Table 1.

In this paper, autism is conceptualized as a difference and an identity before a disability (Kapp et al., 2013), but is recognized as being a collection of difference, disability, and identity (Botha & Cage, 2022). The focus is on the importance of defining the autistic experience through lived experience, and thus autism itself is defined primarily as an identity and way of being rather than by diagnostic criteria.

Table 1

Key Terms

Allistic	simply means “not autistic” (Price, 2022, p. 48).
Autistic Community	people who are, themselves, autistic rather than people who work with or are related to autistic people (Roche et al., 2021).
First Voice Research	refers to research that centers the voices of the population being studied; widely advocated by autistic researchers (Bertilsdotter Rosqvist et al., 2019).
Neurodiversity	is a subset of biodiversity and encompasses all humans. The term has been traced to the autistic activism community of the 1990’s and describes the naturally occurring variability of the human nervous system (Botha et al., 2024; Singer, 1998).
Neurotype	refers to the type of nervous system within this continuum of variations.
Neurodiversity Movement	is a social phenomenon striving towards equity and inclusion for all people, regardless of their neurotype (Botha et al., 2024; Singer, 2019).
Neurodivergent	refers to people whose neurotype does not align with the majority. This includes all people with atypical neurology such as autistic people and those with attention-deficit hyperactivity disorder (ADHD), Down’s syndrome, and schizophrenia (Price, 2022, p. 30).
Neurotypical	refers to people whose neurotype does align with the majority (Price, 2022, p. 30).

The Importance of Autistic People in Autism Research

There is increasing recognition of the necessity of including autistic voices in autism research (Pellicano et al., 2018). Tension between the biomedical and social models of autism has created a division amongst researchers characterized by disagreement about involving autistic people in autism research, how autism is conceptualized, which research goals are worthwhile, and how to identify and address discrimination in research and practice (Botha & Cage, 2022).

The biomedical model of disability views disability as located within the person and as a target to be eliminated or cured (Smart, 2006) whereas the social model locates disability within society and targets the environment or social context to alleviate impairments (Bogart et al., 2022; Botha & Cage, 2022). Researchers subscribing to a biomedical model of autism tend to focus on interventions to reduce autistic behaviours and promote conformity to non-autistic normative expectations, whereas those aligned with the social model tend to focus on ways to alter the environment, social policy, or public attitudes to promote health and well-being for autistic people (Botha & Cage, 2022; Dwyer, 2022).

Interventions designed to reduce observable autistic traits and encourage neurotypical-appearing behaviour can be harmful to the mental health of autistic people, including negative self-perception, chronic exhaustion, reduced ability to manage stimuli, and suicidal behaviour (Hull et al., 2017; Raymaker et al., 2020). There is a strong relationship between the use of medicalized narratives in research and the presence of indicators of ableism in that research (Botha & Cage, 2022). Ableism is defined in this context as systematic discrimination arising from assigning value to individuals based on their level of conformity to societally constructed ideals of normal and desirable intelligence and productivity (Lewis, 2022). Indicators of ableism include *dehumanization*, the denial of a group's full humanity by characterizing them as less developed in areas such as emotional complexity, agency, or morality, or evaluating them as less deserving of the same moral boundaries or basic rights as others; *objectification*, the tendency to treat all persons of a group as interchangeable rather than individual, or disregard their autonomy and treat them as instruments for one's own purposes; and *stigmatization*, strong stereotyping and restricting one's view of the individual to stereotypes associated with their disability (Botha & Cage, 2022). Including or consulting autistic researchers could help all researchers conduct research that is more likely to help, and less likely to harm, autistic people (Chown et al., 2017).

It seems self-evident that for research to be as valuable as possible, it must be based on an accurate understanding of the phenomena being studied. Autistic researchers (Chown et al., 2017; Pukki et al., 2022) and advocates (Autistic Self Advocacy Network, 2018) argue a great deal of autism research does not have such a basis, and frequently level two primary criticisms: (1) that it is overly pathologizing, and (2) that it largely excludes autistic voices in favour of autistic people's parents, educators, and healthcare providers (Bottema-Beutel et al., 2021; Kapp et al., 2013; Leadbitter et al., 2021).

The pathologizing model ignores autistic strengths, works from the assumption that autism requires treatment, and tends to characterize differences as deficits (Botha & Cage, 2022; Mitchell et al., 2021). Such assumptions create a significant risk of bias and common sense suggests they must skew the research questions being asked. By excluding autistic voices and relying on reports from third parties such as parents, educators, and clinicians, the bulk of autism research lacks important data and context (Bertilsdotter Rosqvist et al., 2019; Pukki et al., 2022) and frequently fails to align with the needs of autistic people as defined *by* the autistic community: people who are, themselves, autistic rather than people who work with or are related to autistic people (Leadbitter et al., 2021; Pellicano et al., 2018; Roche et al., 2021; van den Bosch et al., 2019).

Allistic (non-autistic) researchers and the use of a medical model framework for approaching both autism research and autistic people can lead to autistic people distrusting researchers and their intentions, which limits their participation in research (Milton, 2014). Autistic participants report the presence of an autistic researcher makes participating in autism research an easier and more positive experience, and the inclusion of autistic researchers can improve the quality of the data collected as well as improving participant recruitment and retention (Pellicano et al., 2022). The presence of autistic researchers in autism research is of critical importance for producing quality research and supporting meaningful connection between research and practice (Kourti, 2021; Milton, 2014).

Positionality

Within this complex social context, researchers bear the significant responsibility of ensuring their research is not only respectful of the autistic community but that it seeks to benefit autistic people. Research targeting interventions to make life easier for family, educators, clinicians, and other support people of autistic people is not necessarily in the best interests of autistic people. Reflexivity by autism researchers regarding their own biases, assumptions, and positionality relative to the autistic community is critical to responsible autism research because epistemology and axiology directly influence the type of knowledge researchers gain from their work (Bertilsdotter Rosqvist et al., 2019).

It is therefore important to describe the author's position. I am autistic, a parent of an autistic child, and a member of the autistic community. My perspective is that of an autistic person with lived experience of the ways in which I have been misunderstood and mistreated as an autistic person both before and after my diagnosis (which I received well into adulthood) and the knowledge I hold from participating in autistic spaces where other autistic adults share their thoughts and personal stories openly and honestly. My experiences interacting with public school systems in two Canadian provinces to access appropriate support for my autistic child also heavily inform my perspective and my research interests.

I simultaneously accept scientific findings that autism results from biological differences in neurological functioning and recognize that a great many of the resulting behavioural and processing differences are problematic only within a societal context. I acknowledge that some aspects of autism are inherently disabling and respect the diversity of experience, perspective, and support needs that exist within the autistic population. I do not presume to represent all autistic people and aspire to do work that accurately and respectfully describes autistic experiences even when they are different to my own.

It is, of course, impossible to separate these aspects of myself from my work, and I do not consider this a weakness. A variety of perspectives, including autistic perspectives, are

necessary to create quality autism research (Bertilsdotter Rosqvist et al., 2019; Botha & Cage, 2022; Chown et al., 2017; Kourti, 2021; Milton, 2014; Pellicano et al., 2022; Roche et al., 2021; van den Bosch et al., 2019). Only by including autistic researchers and participants in autism research can the scientific community hope to conduct research which supports the autistic community in ways that are meaningful to us.

Background

Autistic Students in the Classroom

Autistic children are less successful in the school environment than their peers as measured by both attendance and academic achievement. School attendance is not well studied in Canada (Smith et al., 2022), so we must look to international statistics. Nearly half of autistic students in the UK are absent at least 10% of the time (Totsika et al., 2020). Attendance problems are most common among those attending mainstream schools and result primarily from anxiety and school refusal (Totsika et al., 2020). Absenteeism rates and causes are similar in Norway (Munkhaugen et al., 2019) and Australia (Adams, 2022). Overall, fewer than one third and perhaps as few as one in ten autistic children achieve full school attendance, and they miss three to four times as much school as their allistic classmates (Adams, 2022; Totsika et al., 2020).

Autistic students' academic achievement is poor compared to their peers when controlling for ability levels even in the presence of supportive programming (Ashburner et al., 2010). A review of 19 studies found that autistic students without intellectual disability perform poorly compared to their peers, and that this discrepancy increases with age (Keen et al., 2016). The reviewers also pointed out we have little quality research into whether interventions impact academic achievement or how they do so, and call attention to a gap between research-based understanding of heterogeneous learning profiles among autistic students and the practices being used in classrooms.

This heterogeneity complicates the question of what constitutes appropriate support and intervention. While autistic students are more likely to demonstrate lower achievement, their achievement profiles are spread across the same range as typically developing students (McDougal et al., 2020). This variability relates to broadening diagnostic criteria for autism, and interventions do not yet adequately reflect the varying abilities and needs of autistic people (Charman, 2015). Teachers are left with tools developed for a more homogenous conceptualization of autism and do not have the knowledge to develop more personalized programs for their students (Ducarre, 2023; Keen et al., 2016; Tamm et al., 2020).

Nova Scotia Classrooms

Teachers in Nova Scotia (NS) are aware the training and tools available to them are inadequate for supporting their autistic students. They feel under-equipped to support their autistic students in the classroom and express a strong desire for more and better training (Corkum et al., 2014). It is interesting to note that while classroom teachers in Nova Scotia are responsible for education and planning for all of their students (Nova Scotia Department of Education, 2012, p. 3), they report less training and lower confidence levels than teaching assistants and other support staff (Corkum et al., 2014).

Given that autistic students in multiple countries with differing education systems display similar difficulties with school refusal, academic under-achievement, and feeling unsupported, it seems that a new approach to identifying their needs is warranted. As discussed below, there is a complete absence of research investigating the needs of autistic students in Nova Scotia from the perspective of the students or their families, and very little such research from anywhere in Canada. The NS Department of Education and Early Childhood Development has engaged in significant policymaking activity related to inclusive education in recent years, including the *Students First* report (Njie et al., 2018), the subsequent adoption of the Inclusive Education

Policy (NS Department of Education and Early Childhood Development, 2020), and an ongoing review of the new Policy (Whitley & Hargreaves, 2020).

While these documents highlight the need for improved autism supports, professional development related to autism, and the adoption of an autism strategy, they all identify autism related issues as described by school staff with no attention to first-person perspectives of autistic students (see Njie et al., 2018; Whitley & Hargreaves, 2020). This is inconsistent with the Inclusive Education Policy, which states that inclusive education values and draws upon student voices (NS Department of Education and Early Childhood Development, 2020, Section 4.4). Attempting to define the needs of autistic students without the input of autistic students runs counter to the goal of inclusion.

Inclusion and Participation

Inclusion and participation at school of course are related to attendance and academic achievement. They are also important predictors of adult participation in society for people with disabilities, including autistic people (European Agency for Special Needs and Inclusive Education, 2018). However, the concepts of inclusion and participation must be carefully defined if they are to be meaningfully applied in the school setting (Olsson & Nilholm, 2023).

A recent review of research about school inclusion for autistic students (Lüddeckens, 2021) illustrates how profoundly the inclusion of first-person autistic voices relates to the knowledge produced. Lüddeckens found the very definition of inclusion used by researchers in their study varies with the type of participants they include: those collecting data from parents and teachers define inclusion by physical presence in the classroom and assume that physical presence will result in social inclusion while those focused primarily on autistic students' perspectives define inclusion by achieving social acceptance and participation from the student's perspective.

The relationship is, of course, correlational and not causal; researchers interested in inclusion as defined by social acceptance are more likely to conduct research with autistic participants (Lüddeckens, 2021). What is perhaps most significant is that *only* studies with autistic participants can meaningfully examine acceptance as it is experienced by autistic students, as feelings of acceptance cannot be validly measured without information from the people in question (Hodges et al., 2022). Physical presence in the classroom is not inherently meaningful, and even observed active participation in classroom activities and routines does not fully capture inclusion. Autistic students, like anyone else, require a sense of belonging to feel included at school (Hodges et al., 2022), and only they can tell us whether they feel this way.

Current Practices in Nova Scotia

Behavioural interventions based on applied behavioural analysis (ABA) are standard practice for autistic children in Nova Scotia. The publicly funded programs offered to preschool and elementary aged children, Early Intense Behavioural Intervention (EIBI) and Strategies for Teaching Based on Autism Research (*Support for Autism Spectrum Disorder*, 2017), are based on ABA principles (*STAR Program*, n.d.; Tsiplova et al., 2019). Within schools, the tools recommended for classroom use in the NS Department of Education's *Developing and Implementing Programming for Students with Autism Spectrum Disorder* are dominated by ABA and its derivatives (Nova Scotia Department of Education, 2012, pp. 58–72, 125–137). Problematically, this document references an outdated version of the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., revised; DSM-4-TR) (American Psychiatric Association, 2000), which was replaced with the DSM-5 (American Psychiatric Association, 2013) and its subsequent text revision DSM-5-TR (American Psychiatric Association, 2022).

Furthermore, the overall tone of *Developing and Implementing Programming for Students with Autism Spectrum Disorder* (Nova Scotia Department of Education, 2012) is predominantly deficit-based, focusing on ways in which autistic students are incapable and

terming differences in a negative light by default. Ableism indicators described by Botha and Cage (2022) are used consistently and frequently throughout. Autistic students are described as having a “marked lack of awareness of the existence of feelings of others” (Nova Scotia Department of Education, 2012, p. 9), demonstrating aloofness by “treating people as if they were inanimate objects or useful tools” and “failing to enjoy or return other people’s affection” (Nova Scotia Department of Education, 2012, p. 10). This almost perfectly parallels the exemplar quotes Botha and Cage (2022) use to describe dehumanisation, that autistic people may “demonstrate an apparent absence of empathy for people’s feelings, lack of responsiveness, awareness of social cues or cultural norms”. Autistic students’ cognition is described only in terms of deficits, such as a reliance on pattern recognition in learning preventing meaningful understanding of the material (Nova Scotia Department of Education, 2012, p. 21) with no acknowledgement that exceptional pattern recognition abilities can be a strength such as in visual search or when debugging computer code (Proff et al., 2022).

Peer support is recommended for improving social interactions between autistic and allistic students, but the peer support model described is entirely one-sided (Nova Scotia Department of Education, 2012, pp. 100–101). It involves teaching allistic students how to lead their autistic classmates in neurotypical play and socialization and does not acknowledge that autistic play or social norms exist (Bertilsdotter Rosqvist, 2019; Crompton, Hallett, et al., 2020; Crompton, Ropar, et al., 2020; Heasman & Gillespie, 2019; Petrina et al., 2014; Solomon, 2015). This model of peer support teaches allistic children their autistic classmates are deficient (Bertilsdotter Rosqvist, 2019) instead of teaching all students about differences and the importance of working to understand and appreciate one another (Alkhaldi et al., 2019; Edey et al., 2016; Heasman & Gillespie, 2018; Milton, 2012).

Assessing the Evidence for Behavioural Interventions

Given their widespread use in classrooms and public health programs in Nova Scotia, the weakness of the evidence for behavioural interventions in autism is alarming. Multiple reviews have concluded the evidence for behavioural therapy and EIBI is weak based on the quality (Sandbank et al., 2020) and ecological validity (Lopata et al., 2020) of the studies. There are few randomized control trials and little to no replication, poorly defined therapeutic procedure hinders replication in research or practice, lack of reporting on adherence to the proscribed course limits data describing the impact of different treatment schedules, poor experimental controls prevent analysis of which elements of the therapy contribute to observed effects, and there are questions as to reliability and bias due to poor research design and measurement methods (Caron et al., 2017; Kasari & Smith, 2013; Reichow et al., 2018; Rodgers et al., 2021; Sandbank et al., 2020). Taken together with Keen et al.'s (2016) conclusions about our poor understanding of whether and how common interventions work, there is significant cause for concern that these practices remain at the forefront not because they are of good quality, but because they are all that is available.

It is worth noting the outcome measures of intervention research often do not align with the neurodiversity model. The neurodiversity model is a theoretical framework that acknowledges the full spectrum of human neurotypes as equally valid, challenging notions of ability or disability by accepting these inherent differences between people as normal variations (Dwyer, 2022). From this perspective, and in contrast to the biomedical model, supporting autistic people primarily requires facilitating changes at the environmental or societal levels. Interventions targeted at changing the individual (e.g. medication, skills training) are thus secondary, and only employed when environmental or societal changes can not address an individual's needs and the interventions promote the individual's well-being by reducing distress or dysfunction (Dwyer, 2022). Extant research frequently measures a reduction in observable autistic traits rather than an increase in the autistic person's quality of life (Botha & Cage, 2022;

Dawson et al., 2022; Leadbitter et al., 2021). This introduces the additional concern that, if the interventions are effective, they are effective at producing outcomes which do not align with the goals of fostering acceptance and inclusion.

Implications for Classrooms in Nova Scotia

In addition to NS teachers feeling underprepared to support students, the tools they do have are outdated, are presented in an ableist framework, and are based almost exclusively on practices which are only weakly supported by scientific research. Autistic students often feel overwhelmed by the overuse of these common intervention practices and that they are applied indiscriminately based on their autistic "label" and with poor understanding of when and how a particular strategy would be helpful and no awareness they can be harmful (Aubineau & Blicharska, 2020; Brownlow et al., 2021; Goodall, 2018; Penney, 2013). Classroom environments built on this foundation seem unlikely to be the best we can do to meet autistic students' needs for a sense of belonging. The evidence points to a significant opportunity to improve the way we support autistic students at school. Improving teachers' understanding of autism as it is experienced by students would allow teachers to accommodate individual students with greater flexibility and success (Keen et al., 2016).

What Do Autistic Students Say? A Review of Existing First-Voice Literature

When asked, autistic students tell us directly that the adults in their schools do not know enough about autism to support their success. Only 3% of autistic students in Australia feel their educators are "definitely" well-informed about autism; two thirds say they are not (Autism Spectrum Australia (Aspect), 2013b). Autistic adults in Australia identify insufficient support for their learning needs as having negatively impacted their academic success as children (Autism Spectrum Australia (Aspect), 2013a).

First-Voice Research from Canada

Autistic high school students and their families in Newfoundland also feel unsupported and that educators are poorly informed (Penney, 2013). They feel their schools often fail to provide a safe environment appropriate to the student's needs, experience a disconnect between the supports or interventions used and the underlying cause of the targeted behaviours, and perceive school staff as lacking the knowledge and skills to support autistic students. Though classroom teachers were employing interventions which they presumably believed to be good practice, the children felt devalued, ignored, and unsupported. Many families also reported important accommodations outlined in their child's Individual Program Plan (IPP) were not implemented, suggesting the teachers did not consider these documented accommodations valuable (Penney, 2013).

Autistic students in Québec struggle to find meaningful inclusion at school, and their comments indicate that poor understanding of their needs and inner experience contributes to this problem. The students report that managing the sensory environment, difficulty with bullying and peer relationships, and fatigue all inhibit their experience of inclusion at school (Aubineau & Blicharska, 2020). Of particular interest, fatigue includes feeling overwhelmed by support services which, while helpful in moderation, often consume so much time there are no quiet moments left during the school day and insufficient time to decompress and rest at home. The extent of intervention and support given these students appears to align with the deficit-based and intervention-forward approach recommended in NS classrooms (Nova Scotia Department of Education, 2012), raising the question of whether students in NS feel similarly.

On an optimistic note, these students also described factors that enable school inclusion (Aubineau & Blicharska, 2020). These include motivation to succeed at school derived from personal goals and interests, participation in a specialized curriculum aligned to their skills or interests, and having a close friend at school who shares some of their unique characteristics such as disability or shared "geek" interests. Within student's comments about special

curriculum is an important observation that the smaller classes and consistency of the student group are valuable and much preferred to the constant switching of classrooms, classmates, and teachers typical in Canadian high schools. Insights such as these can provide concrete direction for research and practice (Aubineau & Blicharska, 2020).

The two studies described above (Aubineau & Blicharska, 2020; Penney, 2013) are the only first-voice research of Canadian autistic students' school experiences the author could locate after extensive searching, including reaching out to an international network of autistic researchers who research autism. An excellent and up-to-date scoping review of qualitative research on autistic students' school experiences identified 27 such studies from the UK, 7 from Australia, and 4 from the USA (Taneja-Johansson, 2023). The bulk of the extant literature describing autistic students' experiences of school comes from the UK and Australia.

Common Themes in First-Person Research

The Québec students' observations about excessive support services (Aubineau & Blicharska, 2020) echo those of autistic youth and young adults in the US. When reflecting on their high school experiences, they say that removing barriers to genuine social interaction is important to school participation (Bottema-Beutel et al., 2016). Such barriers include adult involvement in social situations or designing social interactions to target therapeutic goals such as teaching or practicing social skills. Instead, opportunities to pursue shared interests with their peers are the most valuable way to build friendships, and this desire for reduced intervention and support also aligns with factors the Québec students described as important (Aubineau & Blicharska, 2020).

Autistic high school students in the US regard their autism as negatively impacting their school experience because they feel separated or excluded from their peers (Bottema-Beutel et al., 2020). This supports the importance of focusing on *meaningful* inclusion and participation at school. Like autistic students in Australia (Autism Spectrum Australia (Aspect), 2013), American

autistic students want school professionals to have more information about autism itself, and knowledge of more strategies and accommodations (Bottema-Beutel et al., 2020). This underscores the need to create better training programs for teachers.

In England, students can be “excluded” from school for their behaviour and are then provided with alternative education (Brede et al., 2017). A group of autistic middle and high school students enrolled in an alternative program shared a common history of initially enjoying school but experiencing declining engagement and school refusal as the school environment and expectations became more complex over time. The students described social isolation, cognitive fatigue, and feeling let down by school staff who they perceived as unhelpful, unfair, and inconsistent. Students and their parents described staff failing to respond with strategies appropriate to the individual students’ needs and confusing the student’s need for support with willful misbehaviour. This negative environment created increasing distress for the children, leading to more difficulties with attendance and self-regulation, until the children were excluded (Brede et al., 2017).

Thankfully, these students re-integrated into mainstream school successfully and their experience provides more clues about how to improve classroom practices. Factors for successful reintegration included adjusting the physical environment, staff working to build the child’s trust, thorough staff training regarding the individual student’s needs, and staff’s acceptance of the validity and importance of the needs identified by the students and their families (Brede et al., 2017). Again, autistic students describe the importance of school staff having a genuine understanding of autism and the ways in which the student experiences their school environment.

Finally, a recent review of first-voice research on autistic students’ school experiences confirms the themes evident throughout this literature review (Ducarre, 2023). The review identified broad heterogeneity in autistic students’ educational needs and preferences, requiring a better understanding of the diversity of autistic presentations and a shift towards individualized

programming from ready-to-use methods. Autistic students provide widespread accounts of support practices being used in situations where they are not helpful and at times are counterproductive and harm students' participation or trust in their teacher, again suggesting that teachers need a deeper understanding of autism and autistic people to better align responses to their students' needs. Students overwhelmingly crave being understood as individuals and their genuine, autistic selves. Teachers' understanding of and attitude toward autism is widely reported as being critical to positive school experiences. The importance of inclusion at school is common across studies, and autistic participants define inclusion as a feeling of belonging and being respected (Ducarre, 2023).

Taken together, the reviewed literature points to *understanding* as the single most significant barrier, but also the single greatest opportunity. Autistic students' needs are rooted in their unique way of being and perceiving. Supports must align with the experiences and needs which underlie their behaviours and with their self-determined goals for success.

Summary of the Literature Review

A robust body of research investigating school staff's perceptions consistently identifies limited knowledge about autism and lack of training on appropriate support measures as hindering teachers' ability to best support their autistic students. The heterogeneity of autistic students' needs, abilities, and presentations further complicates matters, as teachers cannot successfully respond to each individual with such limited knowledge and tools. Research of students' perspectives is an emerging field, but the available evidence consistently indicates staff's lack of understanding about autism contributes to barriers to inclusion, participation, and success. Both educators and autistic students have identified the need for teachers to have a deeper understanding of how autistic students experience school, which requires collecting data about their experience.

The Present Study

It is evident that teachers need and want a more authentic understanding of autism and their autistic students. While there is a great deal of consistency in the literature examining autistic students' first-person school experiences, the limited data from Canadian students and complete absence of data from Nova Scotian students is a research gap worth addressing.

School staff's understanding of autism directly contributes to barriers autistic students face to participation and inclusion, and the supports and interventions provided to students significantly impact their experience of meaningful inclusion – not always positively. The nuance of these factors may be unique in Nova Scotia schools. The existing training and development programs teachers have access to, the school culture facilitated by our Regional Centres for Education, and the broader societal context of Nova Scotia itself may all impact the precise nature of autistic students' experiences in Nova Scotia schools. We will certainly never know unless we ask them.

Therefore, this qualitative study describes first-person accounts of school experiences from autistic students in Nova Scotia. This study has two important goals. First, to identify what autistic students in Nova Scotia want their teachers to know about their school experiences as they relate to inclusion. Second, to gather stories that exemplify their experiences.

Research Question

How do autistic students in Nova Scotia describe their experience of inclusion at school?

Methodology

Research involving autistic children as participants requires creativity to make participation accessible (Harrington et al., 2014). The challenges of conducting such research have historically been viewed as limitations inherent to an individual's diagnosis or abilities, but reflecting on research practices can identify limitations which are inherent to conventional methodology (Booth & Booth, 1996). Identifying our unexamined assumptions about how

research is conducted allows us to challenge these assumptions to improve the quality and accessibility of our research and is consistent with the social model of disability. Flexibility in research design to accommodate participants from a broader population can improve the representativeness of the sample (Nicholas et al., 2019), and a willingness to challenge methodological conventions is necessary to produce quality autism research (Bertilsdotter Rosqvist, 2019; Chown et al., 2017).

The bulk of research similar to the present study has used semi-structured interviews (SSI) (Nicholas et al., 2019), but methodological details such as interview protocol are often poorly explained (Fayette & Bond, 2018; Jivraj et al., 2014; Tyrrell & Woods, 2020). Supportive practices such as the use of visual aids, accepting alternative communication, and adapting open-ended questions have been found to improve the quality of data collected via SSI with autistic participants (Courchesne et al., 2022; Nicholas et al., 2019; Tyrrell & Woods, 2020), and such measures have been incorporated into the present study. In recognition of the importance of describing methodology to contribute to improving autism research, detailed interview protocol is provided (Appendix A).

Emancipatory Research

Emancipatory research is that which actively seeks to remove disabling societal barriers (Chown et al., 2017). Chown et al. created a widely-cited framework for conducting emancipatory autism research that is inclusive and ethical. This framework has been embraced by prominent autistic researchers including members of the Global Autistic Task Force on Autism Research (Pukki et al., 2022), Monique Botha (Botha & Cage, 2022), Steven Kapp (Bottema-Beutel et al., 2021), and Hanna Bertilsdotter Rosqvist (2019). The present study meets Chown et al.'s requirements for emancipatory autism research, including having an autistic researcher identify and define the matter being investigated; subscribing to the social

model of disability with research goals focusing on improving the lives of autistic people; and autistic ownership of autism research.

Emancipatory research challenges researchers to examine biases and limitations implicit in academia. Collaborations between autistic and allistic researchers are necessary, wherein allistic researchers seek to learn and understand autistic perspectives to align research with autistic priorities (Bertilsdotter Rosqvist et al., 2019). The present study is such a collaboration, with an allistic supervisor providing support to an autistic researcher, including the freedom to challenge typical methodology in the pursuit of autistic-generated knowledge.

Ethical Considerations

Careful consideration has been given to ethics in designing the present study. The inclusion of autistic participants and researchers is a cornerstone of ethical autism research (Chown et al., 2017; Pukki et al., 2022). While critical to responsible research, the inclusion of autistic children as participants necessitates careful planning to ensure they are treated fairly and ethically. Each participant was invited to complete a pre-study survey (Appendix B) to identify accommodations, communications needs, and indicators of distress to minimize any stress or discomfort involved in the interview. Participants were given the choice of completing the interview in their homes or at the University, and the freedom to choose whether their parent/guardian was present during the interview.

Meaningful assent is critical to the ethical integrity of this study. To support meaningful assent, the Statement of Assent (Appendix C) was written by the primary investigator since communication between autistic people is more effective than that between allistic and autistic people (Crompton, Ropar, et al., 2020; Milton, 2012, 2014), and reviewed by the thesis supervisor, an experienced school psychologist, to confirm that the language used is age-appropriate and accessible. The primary investigator reviewed the Statement of Assent with participants at the interview, which again capitalizes on the success of autistic-autistic

communication. Participants were asked on the pre-study survey to identify signs of distress the interviewer could attend to and any signal they wished to use to indicate “stop the interview”. Finally, communication cards were provided to all participants to provide an alternative communication option for important needs such as ending the interview, taking a break, or needing their parent (Figure 1).

This study protocol received clearance from the MSVU Research Ethics Board (2023-105).

Participants

Sampling method

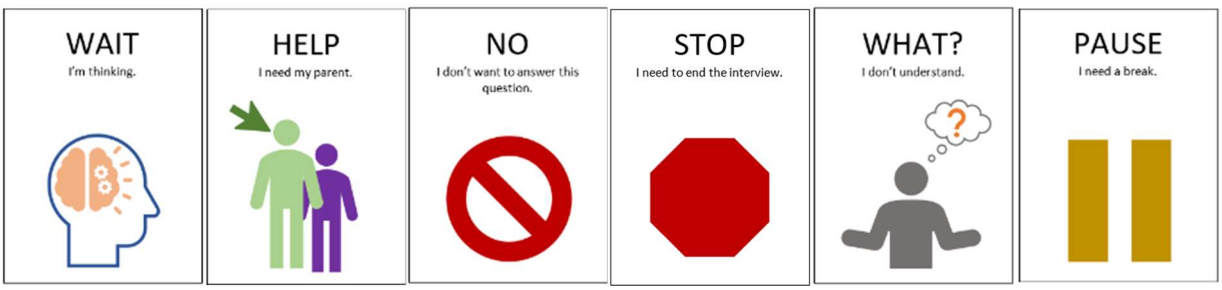
Purposive and snowball sampling (Etikan, 2017) were used to gather the sample for the present study. Participants were selected to create a gender-balanced sample who attend school in several different communities. The primary researcher advertised the study in social networks available to her as a member of the autistic community.

Inclusion criteria

- Formal diagnosis of autism spectrum disorder or equivalent; child aware of diagnosis
- Has attended public school in Nova Scotia within the past 12 months and for a period of at least one full school year
- Able to participate meaningfully in an interview with an English-speaking interviewer

Figure 1

Communication Cards



- Age 11 years or older (Courchesne et al., 2022; Tyrrell & Woods, 2020)

Participants

The sample consisted of 5 participants, aged 13-15 years. Three identify as female and two as male. All participants identify as white/Caucasian. Four attend schools in the Halifax Regional Centre for Education, and one in a different region of NS. No incentives were provided.

The sample size is justified on the basis of information power (Malterud et al., 2016) and the reflexive approach to data analysis used (see Data Analysis, below) (Braun & Clarke, 2016). Information power posits that the quantity of information contained in a sample is more relevant than the sample size; where each individual contributes significant amounts of data, fewer participants will be needed (Malterud et al., 2016). Reflexivity allows the decision of sample size to made during data collection, as themes across participants' accounts begin to emerge and the researcher can assess whether sufficient data has been collected to provide a rich description that is relevant to research question (Braun & Clarke, 2016). The high degree of sample specificity (autistic students from NS aged 13-15 years) and the richness of the dialogue (Malterud et al., 2016) yielded a data set that provided sufficient information power after 3 to 4 interviews, determined by the consistency of themes and codes across participants. The 5th interview provided confirmation of the themes but no new insights, indicating the themes presented below are adequately represented by the sample.

Research Setting

Participants were provided a choice of setting. To avoid distractions that impact the quality of the interview if held in public spaces (Tyrrell & Woods, 2020), the options offered were a private office at MSVU or the participants' home. Holding the interview in participants' homes is an important option to provide, as many autistic people are most comfortable in their own

space and able to be their most genuine and honest selves at home (Smitten, 2022). Four participants chose to be interviewed at home and one at MSVU.

Informed Consent and Pre-Study Survey

After the participant's parent/guardian gave informed consent, they were provided with the pre-study survey (Appendix B). This survey collected information about the participant's interests and communication needs, as recommended by other researchers (Courchesne et al., 2022; Goodall, 2020; Smitten, 2022; Tyrrell & Woods, 2020). The interview questions were provided at the same time as the pre-study survey. This has been identified as important to accommodate auditory processing difficulties, problems formulating responses and thinking of relevant points "on the spot", and the need for extra time to parse the questions being asked and seek clarification as needed (Bertilsdotter Rosqvist, 2019; Goodall, 2020).

Additionally, participants were invited to bring supporting materials to the interview, such as photos or items that could help them describe their experiences. Such materials can make it easier for participants to give detailed answers (Hill, 2014; Tyrrell & Woods, 2020). None of the participants in the present study chose to bring any material.

Semi-Structured Interviews

A semi-structured interview (SSI) was deemed most appropriate for this study. This is consistent with the existing literature examining first person perspectives of autistic students, and common in all research with autistic children and adolescents as participants (Tyrrell & Woods, 2020). "Autism Voices", a new protocol for interviewing autistic children (Courchesne et al., 2022), also recommends SSI. Additionally, SSI aligns with the recommendations provided by a Children's Advisory Group made up of autistic youth which was formed to help design Craig Goodall's (2018, 2020) studies asking autistic students about their school experiences, providing ecological validity to this choice.

Adaptations to Conventional Semi-Structured Interview Methods

While the use of semi-structured interviews is well supported, the literature is also clear that adaptations to the interview process and the use of supportive tools are necessary to facilitate meaningful participation and allow autistic participants to communicate effectively. Prioritizing emancipatory principles in research (Chown et al., 2017) may challenge methodological conventions (Bertilsdotter Rosqvist, 2019), for example by collecting data using multiple methods across a single data set or the use of alternative data collection such as drawings, but this is justified in order to permit autistic people to participate (Booth & Booth, 1996) and facilitate their providing detailed responses (Tyrrell & Woods, 2020) while upholding emancipatory research principles.

Rather than offering different adaptations to each participant, the tools and accommodations described here were made available to all participants. This universal design approach is foundational to an inclusive interview process, providing accessible pathways to participation for all participants such that each individual may take advantage of whatever tools are helpful to them in the moment (Courchesne et al., 2022).

Adaptations supported by the literature and employed in the present study include offering alternative output methods such as texting or drawing, supplying alternative wording in the interview guide to allow the interviewer to modify abstract questions to be more concrete when needed, and allowing participants some control over the structure of the interview (Courchesne et al., 2022; Fayette & Bond, 2018; Goodall, 2018, 2020; Nicholas et al., 2019; Penney, 2013; Tyrrell & Woods, 2020).

Supportive tools identified in the literature include the use of visual aids to reduce communication or memory demands (Tyrrell & Woods, 2020), the availability of alternative communication tools such as picture cards (Courchesne et al., 2022; Fayette & Bond, 2018; Nicholas et al., 2019) and the use of structured activities (Courchesne et al., 2022). The structured activities used in the present study draw on the suggestions made by the Children's

Advisory Group (Goodall, 2018, 2020) described above and are designed to provide more concrete ways to respond to abstract questions and articulate abstract ideas.

Interview Protocol

The SSI is designed to answer the research questions, using creative adaptations and tools to support meaningful engagement and participation. These tools have been designed based on the studies described above, particularly the Autism Voices protocol (Courchesne et al., 2022) and methods designed by the Children's Advisory Group for Goodall's (2018, 2020) studies. When considering the interview protocol used in this study, it is important to remember that the tools used do not (and are not intended to) function as data collection tools. They are designed to elicit data (words) which can be collected (recorded).

Introduction, Rapport Building, and Obtaining Assent

At the beginning of the interview appointment, the researcher greeted and thanked the participant and parent/guardian and introduced herself. She built rapport by using information provided on the pre-study survey to ask questions related to their interests. The participant and parent/guardian were given the opportunity to ask questions about the study and interview process.

Informed consent was reviewed with the parent/guardian. The Statement of Assent (Appendix C) was provided to the participant, and the researcher went through the form with participants to ensure understanding. Communication cards (Figure 1) were provided to the participant as part of this discussion. These cards gave participants an alternative method for communicating important needs (for example: end the interview, take a break, or need time to think) to facilitate ongoing assent (Courchesne et al., 2022). The interviewer had her own set of communication cards, to normalize their use.

At this time, if the participant and their parent/guardian chose for the adult not to be present during the interview, a return time was chosen and a plan established for the adult and

interviewer to contact each other if necessary. Audio recording began after the participant provided assent and was ready to begin the interview.

Ice Breaker

Participants were given a deck of stock images of schools, including pictures of different locations and activities. They were invited to share any ideas the pictures sparked about feeling included at school. This activity was included in the audio recording and the data set.

Determining Interview Structure

Three main interview questions were used to answer the research question. Each included two sub-questions and associated structured activities, which are described below. The interview began with placing 3 question cards in front of the participant, with one question and the associated sub-questions written on each. The interviewer explained the interview questions and answered the participant's questions about them. The participant was invited to organize the cards to indicate the order in which they wished to answer the questions, consistent with Autism Voices protocol (Courchesne et al., 2022). This provides structure, predictability, and autonomy. These questions are:

- What does inclusion mean at school?
    - What does inclusion mean to you?
    - Does that happen at school?
- What creates genuine inclusion?
    - What can schools, teachers, or students do to help you feel included?
    - What gets in the way of feeling included?
- What do teachers need to know about autism?
    - Do teachers know enough about autism?
    - What do you want to tell teachers about autism, or being an autistic student?

Interview Questions

Following the order determined by the participant, the researcher began each portion of the interview by reading the question and sub-questions aloud and describing their general

intention. The activities involved with each sub-question are described below. The full interview protocol is provided in Appendix A.

What Does Inclusion Mean at School? A card-sorting activity was used to support participants in defining school inclusion and describing their experiences with this definition of inclusion. These definitions drew upon the work of Goodall (2020), the author's own experience, and the literature review (Aubineau & Blicharska, 2020; Penney, 2013). Twelve cards with possible definitions of inclusion were provided to the participant, along with blank cards to add their own ideas (Figure 2).

What Does Inclusion Mean to You? Participants were asked to sort the cards into two piles: things that are part of their definition of school inclusion, and things that are not.

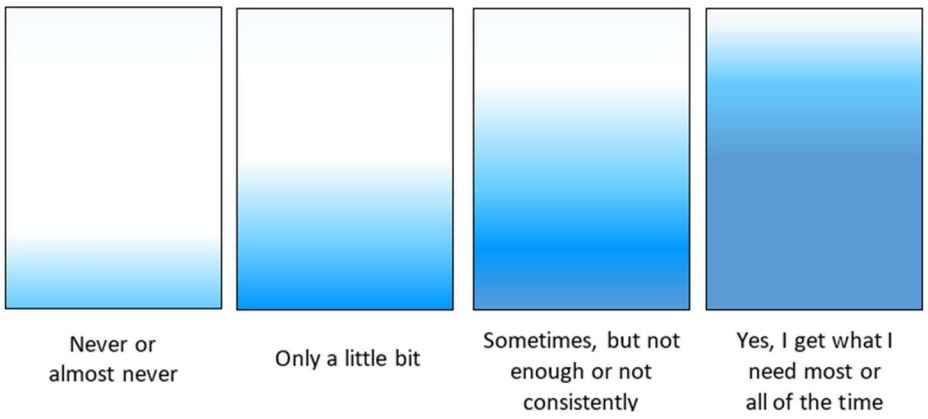
Figure 2

Materials for "What Does Inclusion Mean at School?"

A

Being in the classroom most of the time	Adults helping me socialize or make friends	Completing the same schoolwork as everyone else
Coming to school every day	Working with other students	Able to be my true self at school
People asking my opinion	Keeping my autism private	People asking me what I need
Opportunities to share my knowledge	Students understanding what autism is	Teachers understanding why I need my adaptations

B



Note. Panel A: Items provided on inclusion cards to answer sub-question: "What does inclusion mean to you?" Panel B: Likert scale used to sort items to answer sub-question: "Does that happen at school?"

Does That Happen at School? Participants responded using a Likert scale, rating each item they identified as being part of their definition of school inclusion. A printed rating scale was provided with room to sort each card onto one of the response options.

What Creates Genuine Inclusion? A different card-based activity was used to identify actions that can be taken to create an environment the participant would find inclusive. This activity used diamond ranking as described by Goodall (2020), beginning with a capacity building exercise sorting foods from most to least delicious.

Cards were provided with nine possible facilitators of, and nine possible barriers to, inclusion. These items are also based upon the literature review and the author's own experience. Participants ranked each set of cards using the diamond ranking board (Figure 3).

What Can Schools, Teachers, or Students Do to Help You Feel Included? Cards with nine potential facilitators of inclusion were provided to the participant, and they were asked to sort the items from most helpful to least helpful.

What Things Get In the Way of Feeling Included? Participants repeated the activity using cards with nine potential barriers to inclusion, and they were asked to sort the cards from least to most problematic.

What Do Teachers Need to Know About Autism? Participants rated teachers' overall knowledge of autism and were asked to describe what they want teachers to know. This was the most open-ended part of the interview, and the interviewer chose from several possible questions and activities to support meaningful conversation.

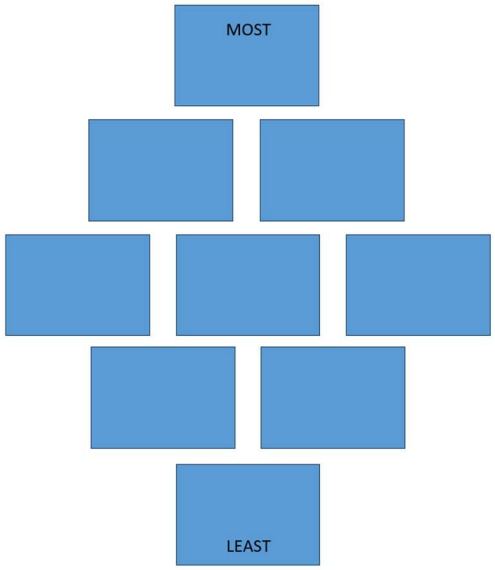
Do Teachers Know Enough About Autism? Participants used a Likert scale replicated from an Australian survey (Autism Spectrum Australia (Aspect), 2013) (Figure 4).

What do you want to tell teachers about autism or being an autistic student? An open-ended activity allowing for multiple output modalities (writing, drawing, speaking) was used to discover what participants want teachers to do differently.

Figure 3

Materials for "What Creates Genuine Inclusion?"

A



B

My teacher(s) understanding me for who I am	Accomodations like using a computer or showing my work differently	Places to go at lunch or recess, like clubs or activities
Having friends at school	Having kids like me in my class	Controlling when I take breaks
Having a space space to go for breaks	My teacher(s) understanding autism	Adapting schoolwork to my interests

C

Classroom environment (too bright, noisy, etc.)	Not having somewhere to go when I'm stressed	Not being allowed to leave the classroom
Being bullied	My teacher(s) not understanding autism	Problems with recess or lunch time
Not understanding what's expected or why I have to do certain things	Schoolwork that's too hard, easy, or boring	Teachers having the same expectations of me as everyone else

Note. Panel A: Diamond sorting board used for both sub-questions. Panel B: Items used for sub-question: "What can schools, teachers, or students do to help you feel included?" Panel C: Items used for sub-question: "What gets in the way of feeling included?"

If you were in charge of hiring a teacher for autistic students, what would you look for?

An activity sheet with a basic clipart figure of an adult was provided.

Interview Wrap-Up

The researcher asked participants if there was anything else they wanted to say before concluding the interview and thanking the participant and their parents.

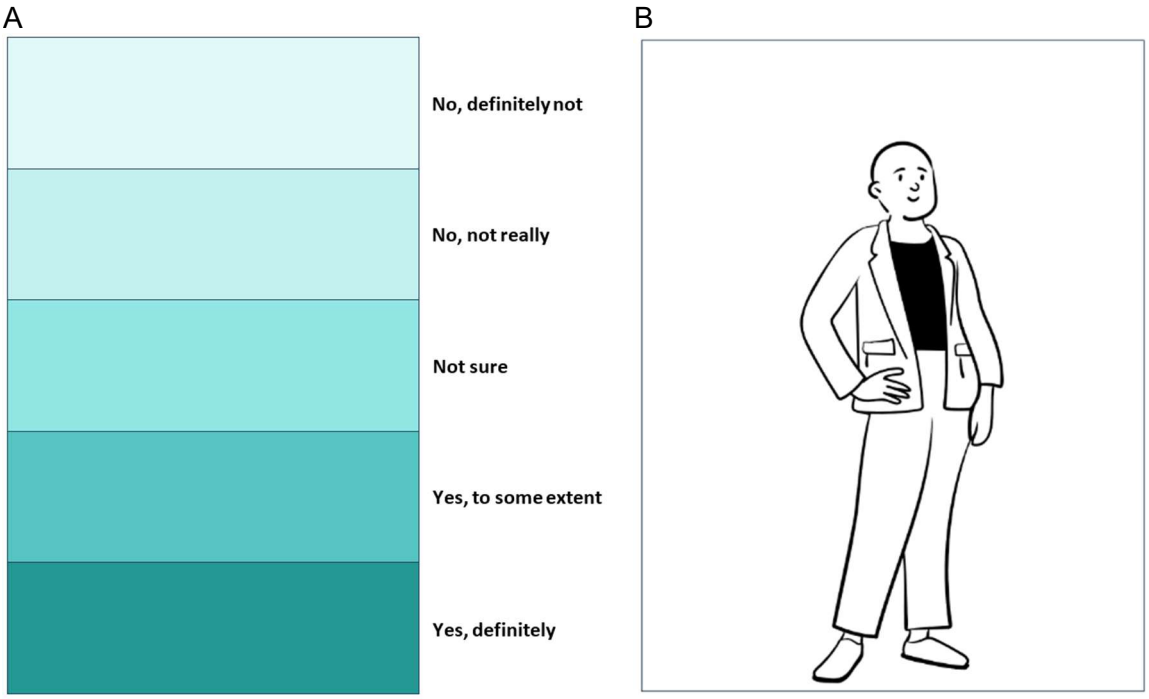
Data Analysis

Ontology and Epistemology

As discussed above (see Positionality), the primary researcher's lived experience and belief in the neurodiversity paradigm significantly influence this project. Ontologically, this project is carried out within the neurodiversity paradigm and by a person with lived experience as a

Figure 4

Materials for "What Do Teachers Need to Know About Autism?"



Note. Panel A: Likert scale used to answer sub-question: "Do teachers know enough about autism?" An arrow was printed separately so participants could move it around during their response. Panel B: Activity sheet used to answer the question: "If you were in charge of hiring a teacher for autistic students, what would you look for?"

late-diagnosed autistic person. This autistic identity is central to this project's epistemology as well; the most fundamental aspects of knowledge production, such as how information is processed or assigned value is shaped by her autistic cognition. An allistic researcher analyzing the same data would likely prioritize different pieces of information and reach different conclusions, and this ontological and epistemological position allows the identification of themes which may be invisible to an allistic researcher and the describing of phenomena or perspectives which have historically been unrecognized (Bertilsdotter Rosqvist et al., 2019).

Analysis

The primary analysis method used was thematic analysis (Braun & Clarke, 2006). This method is appropriate for an honours thesis as it is well suited to use by researchers with

minimal experience, and well suited to this project in particular for its ability to report on the experiences and realities of the participants (Braun & Clarke, 2006). Because this study is the first such study conducted in Nova Scotia and among the first conducted in Canada, the goal of the analysis was to produce a rich description of the data set as a whole. While fascinating depth exists for individual themes within the data collected for this study, this analysis aims to identify themes that are important to autistic students overall. Furthermore, because this study aims to answer a specific research question based up the literature review, analysis was theoretically driven (Braun & Clarke, 2006). That is, codes were developed with the research question in mind rather than identifying research questions based on the data.

Interview recordings were transcribed and transcripts were loaded into MAXQDA, a qualitative analysis program, for thematic analysis. Any notes recorded during the interviews, such as participants' responses using physical materials, were included for clarity. Analysis began with an initial read through the entire data set. Reflective journalling was used to note initial ideas and reactions. Data was not coded at this stage.

Following this initial read, the data was re-read in its entirety and reflective journalling continued. A set of codes was developed by the researcher and documented in MAXQDA, and the first round of coding was carried out. The data set was treated as a whole, with participants' responses to the individual interview questions combined into the themes as appropriate. After initial coding, themes were identified and codes refined in an iterative process until, in consultation with the supervisor, the final coding scheme was defined and themes identified.

Results

The results of the study provide an answer to the research question: How do autistic students in Nova Scotia describe their experience of inclusion at school?

Analysis reveals that autistic students' experiences of inclusion center around three main themes: (1) *Being Myself*, (2) *How My Brain Works*, and (3) *School Doesn't Make Sense*. All

Table 2

Main Themes

Theme	Sub-Themes	
Being Myself (5/5)	My own interests	(5/5)
	Acceptance and understanding	(4/5)
How My Brain Works (5/5)	What are we doing?	(5/5)
	Why are we doing it?	(4/5)
	Demonstrating understanding	(4/5)
School Doesn't Make Sense (5/5)	Listen to me. Believe me.	(4/5)
	Take responsibility	(4/5)

Note. Each of the three main themes and associated sub-themes are shown. The number of participants, out of 5, who spoke about each theme or subtheme is indicated in brackets.

participants (5/5) talked about each of the three themes. Discussion was evenly divided between the themes, suggesting they are equally important to students.

The first theme, *Being Myself*, captures ways in which connections with staff and peers support feelings of safety and belonging. The second theme, *How My Brain Works*, describes common challenges with understanding teachers' expectations, and how this impacts students' ability to learn, participate, and demonstrate their knowledge. The third theme, *School Doesn't Make Sense*, draws attention to problems with the way accommodations and supports are implemented in schools and the impact this has on inclusion. See Table 2.

Theme 1: Being Myself

This theme highlights how feeling comfortable being their true selves contributes to autistic students' ability to thrive at school. Relationships are integral to creating the space for autistic youth to be themselves. Participants described how personal identity and social connections contribute to inclusion in two sub-themes (Table 3), (1) *My own interests* and (2) *Acceptance and understanding*. All participants (5/5) say "Being my true self" is important to inclusion and define being your true self as acting and speaking naturally.

Table 3

Theme 1: Being Myself

Sub-Theme	Description
My own interests (5/5)	How individual interests relate to being your true self and contribute to interpersonal relationships
Acceptance and understanding (4/5)	How acceptance and understanding relates to feelings of inclusion and safety

Note. The sub-themes of Theme 1: Being Myself are described. The number of participants, out of 5, who spoke about each subtheme is indicated in brackets.

> "I need people that understand. That I can talk to and not have to like, weirdly dance around what I want to say. ... It'd be nice if I could say what I want to say without being shunned." *Becky*
>
> "Act like how you normally would or how you want to." *Olga*
>
> "That's basically like, you know, doing stuff like I like to do. … I like to quote movies when I feel bored or just make random sounds." *Joe*

Although it is such an important element of inclusion, most participants (4/5) say they are unable to be themselves at school. They do not feel comfortable being themselves because of how people react, with some (3/5) participants describing fear for their physical safety including one having experienced explicit physical threats. Several (4/5) have experienced negative social outcomes such as bullying or being the subject of hurtful gossip from other students.

> "You are yourself, you're not safe." *Olga*
>
> "I was harassed and I had to switch schools." *Becky*
>
> "When people just whisper about you? I think that's gossiping." Interviewer: How does that feel? "Not so good." *Susie*

My Own Interests

By creating space for autistic students to share their personal interests and knowledge, teachers can provide opportunities for students to feel safe being their true selves. Participants say that forming a connection with teachers through their own interests or shared interests can also make it easier to succeed with the schoolwork in that teacher's class.

> "She's like the nicest teacher I've ever met. I tell [her] what I do every weekend. She's interested in a lot of things. … She, like, tells me how I'm doing. She gets even happier when I do my work." It's easier for Travis to get help in this class because of his relationship with the teacher. "Ohh actually whenever I do my schoolwork with [her] or like do an essay or like I need to come up with ideas or something, and if I don't have any ideas, she comes up with suggestions." *Travis*

> Interviewer: Which classes are easiest to be yourself in? "I think O2. … The teacher's just really nice. Kinda calm I think. She talks about her dogs a lot. … And I'm helping her with her tomato plants." *Susie*

Some participants fear negative social consequences if they share their special interests at school.

> "I don't know if you know this, but talking about [special interest] and knowing a lot about it is not a very good image for yourself." *Olga*

Incorporating those interests into course work can provide a safe outlet. This offers autistic students the opportunity to be themselves at school, including in front of their peers in the case of work they present to their class. Most participants (4/5) recalled specific times they were able to relate a special interest to their curriculum and complete an assignment or presentation about it. They spoke about these projects with enthusiasm and pride.

> "In music last year, you were told you could pick a project and do whatever you want as long it was music related. And honestly, I did the best. … I got a medal for that." *Olga*

> Joe recalled presenting a slide show about his special interest. "I like to tell people about, like, facts about my favourite stuff like [special interest] and all that. My teachers or classmates. … They call me the [Special Interest] Expert! It feels good." *Joe*

Acceptance and Understanding

Getting to know autistic students as individuals creates acceptance and understanding. Participants say it is easier to have their needs met when teachers and peers know them better and accept their differences. Several participants (4/5) said that teachers who know them well make their classrooms available during lunch or other times of day when the students need access to a safe or quiet space, and they say this is very helpful.

> "If I get stressed, I just go to the bathroom for 15 minutes. And they didn't like that. But now they don't really care as much as long as I'm getting my work done. Because they actually realized, 'She is a good student and she's getting things done, like, who cares if she's going to the bathroom for 15 minutes?'" *Becky*
>
> "I [use headphones] in gym class. It's a big, you know, it's the gym! It's big, it's echoey. My ears are: 'No.' … We were in the gym doing something and I couldn't participate because my headphones and it was basketball and I didn't wanna get them broken. So I was sort of sitting off to the side and [my friends] asked the teachers if we could just go to a different classroom and do whatever there. So that they could hang out with me." *Olga*

Some participants say it's easier to feel comfortable and accepted around other neurodivergent students.

> "In yoga there's a lot of other neurodivergent people. So I relate with what they have to say… They might know what you're trying to say." *Susie*

Peer friendships are important. Not all participants have strong friendships at school, but all say they would like to.

> "Well, school sucks without friends. Umm, you were kind of alone, you know, no one to sit next to. And with friends, it's a laugh all day." *Olga*
>
> "Everybody wants to have friends at school because that's just depressing if you don't." *Becky*

Long term relationships with teachers are important to participants because teachers who they've known for a long time understand them better.

> "I feel more comfortable talking to her and she, you know, gets it better. She cares more. … She gets that sometimes I can't speak when I get stressed. She gets that sometimes umm, I just don't wanna do things because I physically cannot. And she just gets more than I feel like other people would." *Olga*

Staff members' lived experiences can also improve students' feelings of being understood. Participants described how these adults seem to 'get it' better. Students feel more likely to be believed by and to receive the support they need from these adults.

> "Some of them are better [at understanding autism] than others. I think [Teacher A], and [Teacher B]. [Teacher A] used to be a psychologist or something. And [Teacher B], I think she kind of relates cause of some of the things she does as well. I think she said she has anxiety." *Susie*

> "My teacher got a concussion and then she didn't like, take a break. She just kept [working], and so then she got worse and worse. And then she finally took a break. And so she actually kind of understands like disability stuff. … If you go to her and say I'm not feeling good, she's like 'Just go. Go sit in the cafeteria and do whatever.'" Interviewer: She believes you? "Yeah, but it's because she has her own experience with it, and cause her son's dyslexic, she understands a lot of, like the like autism-y related things." *Becky*

Summary: Being Myself

The theme *Being Myself* highlights the importance of creating safe opportunities for autistic students to be their true selves at school, particularly by sharing their interests. Student-teacher relationships formed by engaging with students' interests are valuable for creating a sense of belonging, and this contributes to students' participation and success at school. All participants say they want to be liked for who they are.

> "I'd rather not be hated. I think everyone can agree with that." *Olga*

> "I like being liked, as do most regular human beings." *Becky*

When asked how other students understanding autism would make her feel more included, Olga replied:

> "I guess it would make me feel less afraid." *Olga*

Theme 2: How My Brain Works

The theme *How My Brain Works* captures the importance of teachers appreciating that autistic students' support needs result from brain-based differences. When autistic students experience barriers to learning and participation, it is often because they do not understand the information being presented or need a better explanation of what is expected of them. This extends beyond understanding academic expectations to understanding rules they are expected to follow. While participants expressed frustration with teachers who do not provide sufficient explanation, support, or adaptations, they also stressed the importance of learning the same content as their classmates and following the same rules. They want accommodations that enable them to meet adults' expectations and achieve everything of which they are capable.

Participants described challenges with understanding expectations in three sub-themes (Table 4): (1) *What are we doing?*, (2) *Why are we doing it?*, and (3) *Demonstrating understanding*.

Table 4

Theme 2: How My Brain Works

Sub-Theme	Description
What are we doing? (5/5)	Captures participants' experiences with not understanding what is being said or what is expected
Why are we doing it? (4/5)	Describes participants' need for context and understanding the purpose of an activity
Demonstrating understanding (4/5)	Ways in which challenges with understanding or information processing interfere with demonstrating knowledge

Note. The sub-themes of Theme 2: How My Brain Works are described. The number of participants, out of 5, who spoke about each subtheme is indicated in brackets.

What Are We Doing?

All participants (5/5) report difficulty understanding what teachers are saying or asking. They say classwork and tests are formatted in a way that makes participation and success more difficult than they should be. This includes teachers introducing new information, methods, or skills; and providing verbal or written instructions.

New Information, Methods, or Skills. Presenting too much new material at once – especially without providing context – is overwhelming, leading to confusion and interfering with autistic students' ability to process the information.

> "I just have a little bit of trouble during work. You know, like it's just I have a little tantrum first while doing it. When I first see it's like very hard to my brain since it's like all new to me. So I think like better explanation of work I think would help." *Joe*

Written and Verbal Instructions. Participants spoke extensively about difficulty understanding directions. They get confused when wording is nonspecific or has multiple possible interpretations. This is not an attempt to skirt rules or make excuses. Their confusion is genuine and distressing because they want to follow rules and do what is expected. However, they often find themselves frozen by indecision between possible interpretations, making mistakes because they have misinterpreted what was said, or simply unable to proceed because they do not understand the directions. It is frustrating when they break a rule they were trying to follow, or struggle to master a new concept or skill not because the material is difficult for them, but because it has not been explained properly.

> "Sometimes they'll be like, 'Don't go beyond the fence.' But there'll be part of the fence that's like diagonal. And part of it's just not there. Can I go beyond *that*?" *Olga*

> "Well, there is work that's too hard for me that I can't understand, it's just so hard and all that; easy work, that's just like work that literally a toddler could do. Yeah, like 1 + 1 = 2. It just doesn't improve my brain. [Hard work is] just like stuff that I don't understand. … How to do it properly." *Joe*

> "Clarification of what the [test] question means. What it's asking. My mind immediately chooses two options, and then it goes to three, four, five… I don't wanna be here and I just… just choose." *Olga*

All participants (5/5) describe requiring detailed instructions delivered in manageable quantities. They need an overview of what they are working towards and the steps they will take, because this context is necessary for conceptualizing the individual tasks they must carry out to complete the project. Detailed directions for each step are important and should be given along the way. Joe compared this to Lego® instructions. He knows what the final product will be, and the instructions break the build down into several smaller components which each have precise step-by-step directions.

> "Helping you with work when you're having trouble. That right there is like having a very in-depth explanation but without it being too long. So, you know, [students] don't forget. … [Tell me] in little chunks." *Joe*

> "If it's just one assignment that is just one piece of things to do, I need to know all the information for that assignment. But if it's a multi step, you can give me the instructions for that step when I'm doing that step. I need all of the steps, but the specifics for the very end step – I don't need to know that when I'm just at the [beginning], you know? Give that to us once we're at that stage." *Becky*

Why Are We Doing It?

All participants (5/5) describe a need to understand not only what is expected, but why it is expected. Many become overwhelmed when new material is introduced without sufficient explanation or a rationale for why it's being taught. They express frustration with teachers who are unwilling to explain the reasons underlying rules or directions. This can interfere in their relationships with teachers and makes it difficult to engage with their learning.

Participants described an inability to follow directions or complete work if they don't understand why it matters, and want teachers to know they genuinely require this information. They are aware adults sometimes think they are being difficult or disrespectful, and wish

teachers understood they truly cannot make sense of the material without context. They say providing sufficient explanation is an important and valid accommodation.

> Discussing the item: Not understanding what's expected or why I have to do certain things. "It does happen, especially in science class. It's the most hardest and most boring. I'm supposed to learn like atoms and electricity and electrons and I don't know why I have to learn it. She said, 'You just have to learn it.' Like it's not that good of an answer." *Travis*
>
> "I hate not understanding what's expected because I need to know. Why wouldn't I need to know? Or why I have to do certain things. Because I have a problem where I will not follow a rule if I think it's stupid or I don't understand why I have to do it. … I don't understand why we're doing this. So why would I? Why would I listen to him if I don't understand why we're [doing] this? It doesn't make sense!" *Becky*

Sometimes, the only reason something must be done a certain way is convention. While this explanation may not be satisfying, participants appreciate teachers who directly acknowledge this arbitrariness. There is a sense of relief when teachers are honest, in contrast to teachers who can't or won't provide logical explanations.

> "[My math teacher] doesn't use all those math terms, even though our other math teacher said, 'You're gonna have to learn these. That's all you're gonna have to use.' He's like, 'No, no, it's just extra boo higgy. Let's do this.' … Also, he explains things in a way I can understand." *Olga*

Demonstrating Understanding

As described above, participants want to learn. They also want to demonstrate their knowledge to their teachers and do well on assignments and tests. Clear wording is important for understanding exactly what their teacher wants to see.

> "I hate it. That's what I get stressed about. I understand everything else, I know how to do the math, I know how to write something or whatever, I just don't understand the *question*." Interviewer: What could they do differently? "I mean, clarify a few things, I guess. Like stop leaving things vague or confusing." *Olga*

> "I do complete the same work, but then sometimes it's the same but just a bit different. They reword the questions, like how some of the questions are just worded weird." *Susie*

Beyond this, relating course content to things autistic students are interested in can facilitate both learning new content and demonstrating understanding. When questions or instructions are difficult to interpret, they don't know how to identify what information they need to recall or how to present it. Using their own interests and pre-existing knowledge offers a pathway to accessing the correct information and figuring out a way to present it.

> "I was learning the same thing as everyone else, but just in a way that I was interested in in it. It was the same test as everyone else, but I did it on [outside interest], so I gave her lots of information about [that]. I think I did really good. Because I knew how to answer a lot of the questions." *Susie*

> "I'll do work that's not my interest, but like, I won't be as into it. But if it is something I'm interested in, you will get a 2000-word paper, right?" Interviewer: When do you learn most? "When I'm interested." *Becky*

Many (4/5) have a passion for completing high quality, in-depth work when they are truly interested and engaged. They appreciate opportunities to go beyond the assignment criteria at these times and share the full complexity of their ideas and depth of their knowledge.

> "But now at my new school. We're getting a lot of work and it feels like it's more in depth but it's easier to do because we have more information on how to do things. I need things to be in depth. I need in depth instructions and I also need to be able to do it actually in depth… I have to write like *allllll* [the things I know]. … Things that I write don't make sense unless you have all of it. Because that's how my brain is." *Becky*

Summary: How My Brain Works

This theme captures a significant barrier to inclusion and participation. Participants described challenges with understanding explanations of course material as well as difficulty interpreting instructions, directions, and test questions. They talk about this in the context of things not making sense to their brains or their way of thinking, which suggests the adults do not understand how to communicate clearly with autistic students.

Participants also clearly expressed their desires to learn the same material as their peers when they are academically capable of doing so, and to meet their teachers' expectations. They don't want to avoid hard work or difficult subjects. They want access to the same learning, knowledge, and opportunities as everyone else.

> Becky described wanting to catch up in science class after switching schools. "And so I asked her, like, what do I start to catch up? She literally told me, she's like, 'just don't do it. I'll just modify your exam.' And I'm like, excuse me. No, I can't. No, I have to do it. I have to know how to do it. I have to do the unit!" *Becky*

Theme 3: School Needs to Make Sense

The first two themes described how autistic students feel at school and how they think and process information. The third theme, *School Needs to Make Sense*, relates to having their needs met at school. Participants describe their experiences with receiving supports in two subthemes: (1) *Listen to me. Believe me.*, and (2) *Take responsibility* (Table 5).

For an accommodation to meet a student's need, it must be designed and implemented based on an accurate understanding of that need. For example, offering ear defenders to a student experiencing overstimulation from their visual environment would not make school inclusive for that child. Some needs are much more difficult to articulate or understand than this simple example, and participants expressed frustration about the challenges this causes.

Table 5

Theme 3: School Need to Make Sense

Sub-Theme	Description
Listen to me. Believe me. (4/5)	Captures the importance of listening to students and believing them about their needs, in the context of teachers' limited understanding of autism
Take responsibility (4/5)	Describes challenges with having accommodations implemented effectively and consistently

Note. The sub-themes of Theme 3: School Needs to Make Sense are described. The number of participants, out of 5, who spoke about each subtheme is indicated in brackets.

Listen to Me. Believe Me.

All participants (5/5) responded that teachers do not know enough about autism, and most recognize this results from lack of training. Participants emphasize the importance of teachers listening to individual students about their needs and, importantly, believing them. Despite wishing teachers knew more, participants say teachers' lack of knowledge is not as significant a problem as the issues described in Themes 1 and 2. They explain this is because it's possible for teachers to meet their needs simply by listening to and believing them.

> "With… how teachers are taught, they don't understand it, but they still understand accommodations, right? But they don't actually understand autism. … Them understanding autism isn't the most important thing as long as they're willing to listen and give you accommodations." *Becky*

Breaks provide an excellent example of how listening to and believing autistic students allows adults to support them regardless of their autism knowledge. School staff don't need a deep understanding of the experience of sensory overload to believe that autistic students sometimes need breaks and need to be in control of them.

All participants (5/5) say taking breaks from the classroom is very important. They see breaks as such an obvious necessity it seems almost difficult to explain their importance and function, as a person might say they need light to be able to read and have difficulty formulating an answer if someone asked "Why?". The breaks help autistic students self-regulate when they are overwhelmed by stimuli including noise, social interaction, and cognitive input.

> "Classrooms are stupid. Because like there, there's people. There's everyone there and everyone's watching you and the teacher's watching you and it's just small and it's stuffy." *Becky*

> Going for a walk helps Joe think when he's become overwhelmed. "It just helped me to move my legs. … I [can] think more." *Joe*

Participants point out that they are the only person who can tell when they need a break and must be able to control them for them to be useful. In situations where they are not allowed to leave the classroom for a break, they simply go to the bathroom.

> "But sometimes, you know, you have to pee. … And they don't have to know it's a break." *Olga*

Believing the students and allowing the breaks meets' students' need for self-regulation so they can do well in the classroom. Withholding breaks is detrimental to their participation and emotional state.

> "Then I like socially shut down for the rest of the day. And also, less likely to get work done. … Not talking to anyone and just outright ignoring everyone else. Unless of course I'm about to get in trouble. Then I might just stare at them. Which doesn't go very well probably." *Olga*

Neglecting to listen to students can lead adults to create poorly designed accommodations. Adults may have an inaccurate conceptualization of the purpose of the breaks. Assuming a student has a limited threshold for time spent in the classroom might lead them to schedule breaks at regular intervals. This would not be helpful for a student who only needs breaks when they are overwhelmed, which is an unpredictable event. Adults are also guilty of focusing on their own needs, schedules, or priorities instead of the student's.

> "There was this thing where my psychologist was like ohh, we'll just build in breaks through your day and I'm like, but how am I gonna keep track of that? What if, like halfway through class I'm supposed to take a break, but what if we're doing something that I want to stay in halfway through class? What if we're doing something important that I can't miss halfway through class?" *Becky*

> "I have had situations where I was supposed to take a break at some time and I didn't need a break then. … I had a person helping me. ... So you basically have to go on her schedule instead of, you know, something that was beneficial to you. You're basically just stuck until your scheduled break." *Olga*

This act of believing students is an opportunity to support their independence. All participants report using their breaks responsibly, returning to the classroom after a short period and resuming their work. They value being trusted.

> "It's called autonomy. … When you're overwhelmed and need a break - They can't read my mind!" *Becky*

Take Responsibility

This subtheme reveals a significant problem encountered by all participants (5/5). Participants' responses demonstrate a pattern of school staff offloading responsibility for providing supports onto the students themselves, or onto other adults within the school.

> "People asking me what I need? They ask you, but then they don't actually like follow through." *Becky*

Offloading Onto Students. Several participants (3/5) described experiences with school staff either refusing to provide accommodations or asserting they have provided enough help and the student should be able to succeed with the support provided. This complaint can be considered in contrast to the autonomy participants talked about in the first subtheme (*Listen to me. Believe me.*). They seek and accept responsibility for things they can manage themselves, and want help when they need it. Travis says he lost most of his supports because he was doing well with them in place and now teachers expect him to do too much on his own.

> "I struggle in citizenship and science. Those are those are two of my hardest classes. … Because my helpers don't show up." *Travis*
>
> "Like my science teacher gives me multiple sheets every time I have a class there." He described the sheets as being too hard, and not always getting the help he needs to understand. "Yeah, I don't belong in that science class. … She literally expects everything out of me. [The same] as everybody else, but that's not the right answer." *Travis*

Susie has some teachers who stop students from stimming (using self-stimulatory behaviours for self-regulation) yet expect them to stay in the classroom and behave well. She

tries to use stims she can hide from the teacher and thinks it's unfair to expect autistic students to sit quietly without allowing them to stim or take breaks. It is much harder for her to learn in these classes.

Becky says most of her teachers are unwilling to provide alternate explanations, leading to the confusion described in Theme 2. When a teacher takes the time to explain things a different way, she feels like they value her success.

> "They're like more open to change, they're more helpful. … They're not like, 'Well, I'm the teacher. So you have to listen to me.' They're like, OK, I'll try and figure out how I can change it to make it easier for you." *Becky*

Offloading Onto Other Adults. Participants' experiences suggest a pattern of adults shifting responsibility onto other staff members, with students falling through the cracks. This is described by most participants (4/5). Classroom teachers send students to the Learning Center for help without knowing whether the Learning Center teachers are available to provide it. Busy Learning Center teachers send students away without a plan to get the help they were seeking. Teachers say they cannot make accommodations for students without formal documentation in place, while administrators say the student does not qualify for documentation and classroom teachers should provide informal supports. This erodes students' trust in the adults at school.

> "I don't normally ask for help or anything else. I've learned not to rely on teachers." *Olga*

Although she likes being in the classroom and would prefer to stay there, some of Susie's teachers send her to the Learning Center for academic support instead of answering her questions when she needs help understanding assignment instructions.

> "Sometimes they don't really help you the way that you need it. They said, 'Oh, you can go down to the Learning Centre. They'll help you there.' So then [Learning Center teacher] was really busy with some other kids. So then I didn't get that work done. ... So then now I'm missing a lot of the assignment." Interviewer: What did you need help with from your classroom teacher? "I didn't know how to do the things we were doing. … I would get

> behind that way. She didn't help because she was busy doing something else. So then I just wandered the halls." *Susie*

She thinks there's poor communication between the classroom and Learning Center teachers, and in the end, nobody is taking responsibility for her getting the help she needed.

Becky described a mismatch between her need for extensions and the school's extension policy. While her teachers said they understood she might need extra time on some work, they also said they had no control over the policy and therefore she had to request extensions one week before the due date. She works hard to plan ahead, but autistic meltdowns or shutdowns can arise just as unexpectedly and have the same impact on completing her work as things that are routinely accommodated, like illnesses and personal emergencies.

> "I need due dates but also - they didn't understand this. If I can't complete something by a due date and it's the night the thing's due… I need to be given like an extra two days. Because like realistically I can't finish everything if I can't like mentally wrap my brain around it, it's not going to happen. [I need] for them to be like, 'OK, we won't take any marks off.' Like [I'm] not going to know a week before an assignment's due. … Doesn't make sense at all." *Becky*

Overall, this subtheme demonstrates a pattern of disorganized supports that are not accomplishing their goal of helping autistic students succeed or feel included.

Summary: School Needs to Make Sense

School Needs to Make Sense tells a story of opportunities. Teachers and other school staff have an opportunity to believe students when they explain their needs and act on the information. This supports students' autonomy and academic performance. Adults also have an opportunity to accept responsibility for ensuring students receive the help they need, demonstrating to the students they are valued and welcome in their schools.

Discussion

The present study both supports and adds to the existing literature. The findings align with previous research identifying teachers' limited understanding of autistic lived experience as the single greatest barrier to inclusion for autistic students and add clarity by describing more specifically how this problem manifests in schools. Participants' stories challenge some prevalent ideas about autistic students, provide new context to the ongoing discussion about their needs and experiences, and provide reasons for optimism.

Agreement with Existing Literature

The present study confirms that students in Nova Scotia are experiencing feelings of exclusion and being unsupported. Participants' desire for connection and to reach their full potential echo previous findings that autistic people want to be meaningfully included and productive in their communities (Mitchell et al., 2021). The importance of their personal interests to both interpersonal relationships and motivation to succeed academically is consistent with what other Canadian autistic students have said (Aubineau & Blicharska, 2020).

They share the general disillusionment with teachers' ability or willingness to support them that has been previously described, as well as the more hopeful message that teachers who do listen to their needs and believe these things matter have a tremendously positive impact on inclusion and success (Brede et al., 2017). Unsurprisingly, there is variation in what participants of the present study have described. This, too, aligns with what we already know: autism is heterogenous, and the exact needs of individual autistic people are correspondingly varied (Ducarre, 2023).

Challenging Old Ideas

Social Relationships Are Important

Participants do not fit the stereotype of autistic people preferring solitude (John et al., 2018). They need connections, and without them they experience loneliness at school. They

value peer friendships and find support in these relationships for coping with the stresses inherent to being autistic at school. Friends provide safe chances to be their genuine selves, which participants identified as one of the most important elements of inclusion.

Participants said it is not helpful for adults to help them make friends. They are socially aware; they recognize the falseness of contrived situations and feel othered rather than included by such efforts. Their personal interests provide a better pathway for adults to help them form friendships. Creating opportunities for autistic students to engage with and share their special interests, either in their schoolwork or through extracurricular activities, feels more supportive.

Relationships with adults at school are valuable to all the participants and contribute to feelings of inclusion. They are of the greatest importance to those whose peer relationships are not as strong. Some participants are more adult-oriented than others in fulfilling their need for interpersonal connection, and there is a pattern where those who expressed the strongest orientation towards adults placed the lowest priority on peer relationships.

(Mis)Communication

The receptive communication difficulties described in *Theme 2: How My Brain Works* could be conceptualized not as a communication deficit on the part of autistic students, but as a failing of teachers to communicate in a way that is comprehensible. Listening carefully to what participants have said, it is evident they are not being provided with the information they need and that attempts to secure this information are not always successful. For example, requests for clarity on instructions can be misinterpreted as a need for support learning course material; difficulty with imprecise wording can be construed as pedantry or rigidity.

Considering this in the context of the double empathy problem (Milton, 2012), which explains allistic people have equal difficulty understanding autistic people as the other way around, one might reasonably conclude that teachers have a responsibility to learn more about autistic communication. The Gricean maxims of conversation (Grice, 1975) align tidily with the

problems participants have described: quantity (too much information), relation (missing relevant detail), and manner (ambiguous wording). Since communication is a joint activity, teachers must be responsible communication partners. This means engaging in perspective taking of their autistic students to the extent that they can provide the correct quantity of relevant information in a manner that is comprehensible to their listener.

Participants' descriptions of communication-related difficulties challenge the common conception that autistic people are solely responsible. The present study draws attention to the bi-directional nature of communication and the role teachers can play in preventing or repairing communication breakdowns.

Providing New Context

The present study adds nuance to our understanding of autistic students' experiences of school inclusion. The existing first-voice research consistently demonstrates they feel excluded and unsupported. The present study explores these experiences in greater depth and identifies factors contributing to these outcomes from a first-voice perspective.

Teachers' Autism Knowledge

The literature review identified consistent findings that autistic students want their teachers to know more about autism. Participants in the present study place more weight on teachers *listening to and believing them* than on teachers understanding autism. Participants say autism is complex and sometimes difficult for them to understand themselves, and recognize it is simply not possible for their teachers to understand everything about autism or autistic people. The importance of being believed, and thus having agency to get one's own needs met, is a key finding of the present study.

Communicating Across the Gap

Participants spoke at length about issues around understanding information and instructions. They describe significant frustration with teachers not explaining what is expected

and why it matters. This is a very specific aspect of the autistic experience which all participants described, suggesting it is common to many autistic students, and which it seems many teachers do not understand. It has a significant negative impact on their inclusion and participation at school and suggests a target for teacher education.

While participants did identify listening to and believing autistic students as more important than understanding autism, they also said they would like teachers to know more about autism. There is certainly room for some teacher education. By elaborating on autistic students' experiences of being misunderstood at school, the present study provides more specific direction than previous, more general findings that teachers need to know more about what it is like to be autistic. "Being autistic" is so broad and varied a concept that designing and implementing training to address it is an overwhelming proposition. "Autistic communication" is more realistic in scope and can be targeted for maximum impact.

Reasons for Optimism

Listen to me. Believe me. This is a powerful message. It is something any teacher can do with no training or special resources. It does not entail doing everything the student wants. It simply requires that teachers listen to understand, and demonstrate they believe and value what the student has said by doing the things which can be done and engaging in open, problem-solving discussions about things which are difficult to do (Brede et al., 2017). Since adults are prone to misunderstanding autistic children's distress level (Zablotsky et al., 2015), particularly when the child is quiet and well-behaved, the act of listening and believing is critical. Teachers cannot rely on their own perception of what an autistic student is experiencing.

The power of autistic students' interests is just as compelling. Like listening and believing, engaging with autistic students through their interests requires no special training or tools. Students are saying this is more important for social connectedness, motivation, and academic success than most of the programs and strategies teachers have used with them.

Knowing that time spent forming genuine connection with a student over their favourite fandom is more valuable than slogging through a manual about autistic students in the classroom is, hopefully, freeing and uplifting for educators.

The potential impact of improving skills for communicating with autistic students is also worthy of optimism. It is not as immediate and simple as the two points above but is still an accessible goal. The present findings provide actionable direction for teacher education.

Future Directions

The most significant direction for future research arising from the present findings is the creation of a professional development workshop for pre-service and in-service teachers. The present study identifies specific, high-impact targets for teacher training, offering a valuable opportunity to effect meaningful change in our schools. Possible workshop topics include understanding autistic communication styles, learning to recognize autistic-allistic communication breakdowns, and developing effective skills for communicating with autistic students.

It may be interesting to explore correlations between autistic youths' orientation towards peer-peer vs teacher-student relationships, valuation of the importance of peer relationships, and the strength of existing relationships with peers and with adults. If the trend noticed in the present study is indicative of a broader pattern, understanding it could improve our ability to meet autistic students' need for connectedness at school.

Conclusion

Feelings of exclusion experienced by autistic students in Nova Scotia schools are heavily influenced by the students' ability to form relationships that allow them to be their true selves at school. Staff can create an environment that supports a feeling of safety and comfort for autistic students to be themselves. It is important for teachers to shift away from managing autistic students towards a greater focus on connection, including a willingness to listen openly

to and learn from their autistic students. Teachers should be given the freedom to be creative in meeting autistic students' needs and the training to understand how best to communicate with and understand their autistic students. With this, they must accept responsibility for ensuring they understand their autistic students' needs from the students' perspective, and responsibility for implementing accommodations in ways that meet those needs.

We must recognize that inclusion is a dynamic concept which requires everyone in our schools, both students and adults, to exist outside their comfort zones sometimes. Teachers and administrators must be willing to look critically at their current practices and acknowledge opportunities to change and learn.

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Appendix A: Interview Protocol

During these activities, the interviewer should be attentive to opportunities to encourage conversation and ask questions to learn more.

Rapport Building

Before introducing the interview questions, establish a connection with the participant.

- Ask about "Good topics" listed on pre-study survey
- Ask about favourite book, show, movie, hobby…
- Ask why they decided to participate in this study

Ice Breaker. *Materials: Stock images.*

Provide stock images of school activities and places. Ask which places spark ideas about feeling included or feeling not included. Potential follow-up questions:

- What happens when you are in that place/doing that thing?
- Do other people understand what it's like for you?
- What do they need to know?

Introduction. *Materials: Question cards.*

Explain: "There are 3 main questions in this interview. I'll explain a little about each one, and you can decide what order we'll do them in."

Lay the question cards out where the participant can reach them. Read each question aloud and briefly explain the activities associated with that question. Ask participant to arrange cards in order, to determine the interview schedule. Explain they can change their mind and rearrange the cards as we go.

What Does Inclusion Mean at School? *Materials: Inclusion cards; Inclusion Likert scale.*

The interviewer should be attentive to opportunities to ask participants about their experiences, what works well for them, and what needs to change.

"This question is about figuring out how you define inclusion at school, and it has two parts."

1: What does inclusion mean to you?

Give inclusion cards to participant. Include several blank cards so the participant can add their ideas.

Explain: "I have some cards here with different definitions people give for what school inclusion means. I've also got some blank cards so you can add ideas if you want to. I'd like you to make two piles. Put the things that are part of *your* definition of school inclusion in one pile, and the things that aren't into the other pile. I want to make sure I explained this properly, so let's start with these two cards." (Provide "Feeling lonely" and "Feeling welcome" cards to check that participant understands the activity.)

2: Does that happen at school?

Place inclusion card rating scale in front of participant. Use chart to record responses since this might not be well captured by the audio recording. Participants can respond in the way that works best for them, such as pointing to the scale, placing cards on the scale, or speaking.

Explain: “I want to know if the things that are important to you for inclusion happen at your school. I’ve got a chart you can use to answer this question. For each card, tell me whether that happens never or almost never, usually one or two days a week, usually 3 or 4 days a week, or almost every day.”

What Creates Genuine Inclusion? *Materials: Food, facilitator, and barrier cards; Diamond ranking chart.*

“This question is about how to make school genuinely inclusive. I want to know the most important things people could do to make you feel included, and which things get in the way.”

Place the diamond ranking chart in front of the participant. Explain how it’s used, and practice the ranking system using the food cards to answer the question “Which foods are most delicious?” to ensure understanding.

The interviewer can ask questions to elicit stories of participants’ experiences of inclusion. For example: Why did you put this card at the top/bottom? Have you ever experienced <item from card>? Do other people in your class get treated like <item from card>?

Use chart to record responses since this might not be well captured by audio recording.

1: What can schools, teachers, or students do that helps you feel included?
Use inclusion facilitator cards.

2: What things get in the way of feeling included?
Use inclusion barrier cards.

What Do Teachers Need to Know About Autism? *Materials: Knowledge rating chart; Teacher activity sheet.*

“First, I want to know whether the people at school know enough about autism. Then, I’d like to find out what you think teachers need to know.”

1: Do teachers know enough about autism?
Place the knowledge scale and arrow marker in front of the participant. Ask participant to place the arrow marker on the scale to indicate whether teachers know enough about autism.
Potential follow up questions:

- Why did you choose that score?
- How can you tell a person does/does not know enough?
- Have you ever had a teacher who would score at the very top/very bottom of the scale?

2: What do you want to tell teachers about autism or about being an autistic student?
Allow the participant to guide this discussion, because it is important to find out what they believe matters for teachers to know.

“If you were in charge of hiring a teacher for autistic students, what would you look for?”
Provide teacher activity sheet.

- What should they *know* to be a good teacher for autistic kids?
- What should they *do* to be a good teacher for autistic kids?

Alternative questions, if needed:

"Can you think of a time when you missed school or got in trouble at school (that you think was related to being autistic)? Tell me what happened."

- Did the adults understand your perspective?
- What do they need to know?
- Do you think they would have acted differently if they understood? How?

"If you could speak to your teacher directly, what would you tell them?"

Wrap-Up

Thank the participant and ask if there's anything else they would like to share. If the parent/guardian is not present, wait with the child until they have returned.

Ask if the participant or parent/guardian have any questions. Thank them both for their participation.

Appendix B: Pre-Study Survey

PRE-STUDY SURVEY FOR: _____
(participant's name)

Actually Autistic at School: Giving Voice to #ActuallyAutistic Perspectives on School Inclusion

THANK YOU!

Thank you for agreeing to participate in my study. I want it to be a good experience for you. Please tell me about yourself so I can make the interview as comfortable as possible. You can get your parent or guardian to help you fill this in if you like.

COMMUNICATION

When you think about an interview, you might expect it to involve two people speaking to each other. Are there other methods of communication you like to use? For example: typing, drawing, or using an augmentative and alternative communication device.

_____

_____

_____

YOUR AUTONOMY

You are in control of this interview. If you need to take a break or end the interview, that's OK. Sometimes it's hard to say those things out loud, so I will bring communication cards to give you an alternative.

Are there any signs I should know about that would tell me you're stressed out or upset? For example, squirming, picking at your clothes, lying down, or humming.

_____

_____

Is there a different method you'd like to use to tell me you need to stop? Example: a hand signal or code word.

_____

_____

1/3

THINGS YOU DO AND DON'T LIKE TO TALK ABOUT

I'd like to know about any subjects that I should avoid because they're upsetting to you. I'd also like to know about subjects that you find really interesting and enjoy talking about.

Avoid: _____

_____

Good topics: _____

_____

CHOOSE A PSEUDONYM

Protecting your privacy is important. When I write about the things you tell me, I can't use your real name. I'll use a pseudonym (a fictitious name) instead. If you know what name you'd like me to use, write it in the space below. If you don't have one yet, that's OK. We'll figure it out at the interview.

_____

ANYTHING ELSE?

Is there anything else I should know about you? Parents and guardians, you can use this space to add anything you think is missing.

_____

_____

_____

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INTERVIEW QUESTIONS

These are the questions I'll ask during the interview. If anything is unclear, you can ask me about it at any time. You are invited to bring any materials that will help you answer these questions, such as photos of places in your school or objects that can help you explain something.

Introduction: Tell me about your favourite things! If you want, you can bring something to help tell me about your interests.

Questions: There are three main questions, and you will get to choose what order to answer them.

- ***What does inclusion mean at school?***
    a. How do you define it? (I'll have an activity with some ideas to get you started.)
    b. Do you feel that way at school?
- ***What creates genuine inclusion?*** (I'll have an activity with ideas of things that impact inclusion.)
    a. What can schools, teachers, or other students do to make you feel genuinely included?
    b. What things get in the way of feeling included?
- ***What do teachers need to know about autism?***
    a. Do teachers know enough about autism?
    b. What do you want to tell teachers about autism or being autistic?

Appendix C: Statement of Assent

After piloting the interview protocol with autistic youth, it was determined that the assent document could be overwhelming for some participants. The document was separated with each subheading printed on a 4x6” card. Clarifying text was added to these cards (bold type). In this way, participants were presented with only one section at a time and the interviewer could best ensure participants’ understanding of each point before discussing the next.

STATEMENT OF ASSENT

Actually Autistic at School: Giving Voice to #ActuallyAutistic Perspectives on School Inclusion

ABOUT THIS STUDY

The purpose of this study is to collect stories from autistic youth about their experiences at school in Nova Scotia.

Studies like this have been done in other parts of the world. We know that autistic students don't always feel like their teachers understand them, and they don't always feel like their school is inclusive. Hearing directly from students helps the people working in schools know what's working, and what needs to change.

Nobody has ever done a study like this in Nova Scotia. I want to find out what **you** think about **our** schools.

ABOUT THE RESEARCHER

My name is Natalie Lawy, and I'm doing this research project as part of my psychology degree. After I finish this degree, I want to keep going to school so I can work as a psychologist in schools here in Nova Scotia.

I'm autistic too. I think that means I understand what autistic kids are saying better than most adults, and I can use my position as an adult, a parent, and a researcher to get that message across.

If you have questions at any time, you can contact me at natalie.lawy@msvu.ca. You can also contact my supervisor, Dr. Conor Barker, at conor.barker1@msvu.ca.

ABOUT THE INTERVIEW

Our interview will take 60-90 minutes. I'm going to audio record our interview so I have an accurate record of what you tell me. Only my supervisor and I will have access to the audio file. Your interview will be transcribed, which means I will make a written copy of everything we say. Your parent or guardian will be able to request a copy of the transcript of your interview.

You have a lot of control of this interview. You will decide what order we do the questions. You can use any form of communication that works for you, like showing me photos, texting, or drawing.

You can end the interview at any time. You can also choose not to answer any question.

RISKS AND BENEFITS

Talking about school experiences might be stressful or upsetting. You are in control of what we talk about. I will respect your feelings and pay attention to what you need.

I hope this experience will be positive for you. I am here to listen, and I take what you're saying seriously.

CONFIDENTIALITY

Protecting your privacy is important. I won't use your real name, and I'll remove personal information like the name of your school.

The type of study I'm doing uses direct quotes from participants to help explain the findings. This means that after I remove your personal information, I will quote some of the things you tell me during the interview. Anyone who reads my study or sees my presentation will see those quotes.

I have an obligation to report anything you tell me that indicates you are at risk of harm. In that case, I would have to tell the appropriate person, like a social worker or police officer, who you are and what you said.

WHO WILL SEE THIS STUDY?

The results will be shared at two student research conferences in 2024. Professors and students from MSVU and other universities will see my presentation. I hope it will be published in a scientific journal, and that I have the chance to present it at other conferences too. It's possible that lots of different people will see it.

FUTURE USE OF DATA COLLECTED IN THIS STUDY

One of my goals for the future is to create a workshop for educators about autism. I want to tell them more about autism, what it's like to be autistic, and what autistic people really need from their schools.

I would like to use the information you share with me today in that workshop. Including stories from lots of autistic students will make the workshop more authentic and, I hope, make it easier for people to understand what I'm telling them.

It's up to you. I'll only use your stories in the workshop if you say it's OK.

ASSENT

I have read and understood the above information. I have received a copy of this form. I agree to participate in the present study.

Participant's name _____ Date _____

Investigator's signature _____ Date _____

ASSENT FOR FUTURE USE OF DATA

Do you agree to the use of your information in a teacher workshop, as described above?

___ Yes, I agree. ___ No, I do not agree.

If 'Yes':
I have read and understood the above information. I have received a copy of this form. I agree to the use of my information in a teacher workshop, as described above.

Participant's name _____ Date _____

Investigator's signature _____ Date _____

1. ABOUT THIS STUDY

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My name is Natalie, and I'm doing this research project as part of my psychology degree. After I finish this degree, I want to keep going to school so I can work as a psychologist in schools here in Nova Scotia.

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You can end the interview at any time. You can also choose not to answer any question.

I'm going to record our interview.
You decide what questions to answer.
You can communicate however works best.

4. RISKS AND BENEFITS

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I have an obligation to report anything you tell me that indicates you are at risk of harm. In that case, I would have to tell the appropriate person, like a social worker or police officer, who you are and what you said.

I'll quote you in the final study.
I won't use your real name or other personal details.
You get to choose a fake name!

6. WHO WILL SEE THIS STUDY?

The results will be shared at two student research conferences in 2024. Professors and students from MSVU and other universities will see my presentation. I hope it will be published in a scientific journal, and that I have the chance to present it at other conferences too. It's possible that lots of different people will see it.

7. FUTURE USE OF DATA COLLECTED IN THIS STUDY

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I would like to use the information you share with me today in that workshop. Including stories from lots of autistic students will make the workshop more authentic and, I hope, make it easier for people to understand what I'm telling them.

It's up to you. I'll only use your stories in the workshop if you say it's OK.

I want to make a workshop for teachers to teach them about autism and what it's like to be autistic.

I would like to use your stories from today in that workshop, but only if you say it's OK.