CANADIAN JOURNAL OF
Disability Studies
Published by the Canadian Disability Studies Association | Association canadienne d'études sur le handicap

Canadian Journal of Disability Studies

Published by the Canadian Disability Studies Association
Association canadienne d'études sur le handicap

Hosted by The University of Waterloo

www.cjds.uwaterloo.ca

Autistic Students' Experiences of Access: Navigating University in Canada

Parcours d'accessibilité dans le milieu universitaire au Canada chez les étudiantes et étudiants autistes

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Abstract

As more autistic students enter higher education, universities have a growing responsibility to support these students. Many autistic students report not receiving adequate support in postsecondary education (Anderson et al., 2018; Gurbuz et al., 2019). This paper shares the results of a qualitative study on the lived experiences of autistic students at Canadian universities. Semi-structured interviews were conducted by an autistic PhD student with ten autistic students about their experiences attending 16 universities across six provinces in Canada. The results shed light on disclosure and use of accommodations, alongside recommendations for self-accommodations from the research participants.

Résumé

De plus en plus de personnes autistes poursuivent des études universitaires, ce qui augmente la responsabilité des établissements en matière de soutien. Pourtant, beaucoup d'étudiantes et d'étudiants autistes disent ne pas recevoir un accompagnement adapté pendant leur parcours postsecondaire (Anderson et al., 2018; Gurbuz et al., 2019). Cet article présente les résultats d'une étude qualitative sur les expériences vécues par des personnes autistes dans des universités canadiennes. Une doctorante autiste a mené des entretiens semi-dirigés avec dix participantes et participants autistes, qui ont étudié dans 16 établissements situés dans six provinces du Canada. Les résultats soulignent les difficultés liées à la divulgation du diagnostic et à l'accès aux mesures d'accommodement, ainsi que les recommandations des personnes interrogées concernant les stratégies d'auto-accommodement.

Keywords
Autism; Canada; disclosure; accommodation; identity; lived experience; higher education

Mots-clés
Autisme; Canada; divulgation; accommodement; identité; expérience vécue; enseignement supérieur

Introduction

Autism diagnosis rates are increasing in Canada (Public Health Agency of Canada, 2018), and although there is a lack of data on autistic students' enrollment, post-secondary institutions are likely facing increases in this population. There is increasing awareness of the importance of equitable access to higher education and the need for inclusive campus environments for autistic students. However, limited research exists on the experiences of autistic university students in Canada. In addition, autistic people have historically lacked epistemic authority, meaning, the ability or access to contribute to knowledge formation on autism (Frith & Happe, 1999). There is a clear need to hear from autistic students, through autistic-led research to provide diverse insights to other students as well as researchers, institutions, and policy makers.

Autism is an invisible or non-apparent disability that manifests in part as communication and social differences. Framing autism as a disability that is the product of both the condition and the society in which we function permits a balanced examination of autistic experiences and how these can be improved (Brown & Moloney, 2019). Historically, disability has been used to reinforce stigma associated with notions of biological inferiority, much like in other identity groups such as gender, race, and sexuality; however, disability is part of the range of human experiences and human variation. By centring the experiences and perspectives of disabled people, disability studies creates "common ground in the experience of stigma and oppression, in the fight for more positive representations, and in the ongoing struggle for physical and intellectual access" (Dolmage, 2017, p. 10).

Persons with disabilities make up 22% of undergraduate enrollment and 6% of graduate enrollment in Canada (Canadian Commission for UNESCO, 2021). The population of disabled students in Canada is highly diverse. There is no single profile of a typical student or a typical student with a disability. Disabled students face circumstances which need to be navigated and negotiated that their non-disabled peers may not. These may include medical management of their disability, management of assistive technologies, accessible transportation logistics, and accessible housing (National Educational Association of Disabled Students [NEADS], 2018). Students with disabilities, including autism, experience an additional “cognitive load” associated with navigating their lived experience with a disability, both within and external to the educational environment (NEADS, 2018).

The particular traits of autism can be framed as differences, rather than deficits, in communication, social interaction, regulation, and restricted interests or routines. As such, the academic and non-academic barriers and challenges faced at the individual or personal level by autistic students at university include social and communication differences and sensory issues. In a systematic review of the literature on the experiences and supports of autistic university students, Anderson et al. (2017) reported academic challenges such as difficulty understanding abstract concepts, problems with planning, and difficulty with the social demands of class such as working in groups and presentations. Non-academic challenges included problems with social interaction, mental health, sensory sensitives, and the demands of daily living. The study further highlighted how those difficulties negatively impacted multiple dimensions of their post-secondary education and university experience.

While autism exists without a diagnosis, and self-diagnosis is valid, formal documentation is usually required for Canadian students to officially access accommodations and supports at their institution. Part of accessing support also requires varying levels of disclosure, which is complex in terms of both self-identification (Parekh & Brown, 2020) and self-advocacy (Bruce, 2020). While many autistic individuals view autism as neutral, they find society often attaches negative meaning and stigma (Botha et al., 2021). Many students with invisible disabilities entering higher education prefer not to disclose their disability (Moriña, 2022). However, non-disclosure at the university level is not a neutral decision; it has consequences for retention, academic success, and a personal impact (Pesonen et al., 2020). In a literature review by Moriña (2022), the reasons for non-disclosure were wide-ranging and include previous negative experiences, stigma, not considering themselves as having a disability, a desire for normality or a fresh start at this stage of adulthood, and resistance to proving their disability to receive necessary accommodations.

Questions of credibility, where students must demonstrate disability or need in order to receive adaptations or accommodation, force students to not only embrace a disability identity but also to self-advocate. Documentation is generally required to receive accommodations, and in some cases, particularly for autism, diagnosis and documentation can be challenging to access due to barriers to diagnosis, including gendered stereotypes. More boys than girls are diagnosed as autistic at a rate of approximately 4:1 (Loomes et al., 2017). This disparity may come, in part, from bias in the diagnosis criteria themselves, which have historically been established on a male phenotype of autism (Hebron & Bond, 2019). Gender is a factor in how clinicians and educators make decisions in identifying autistic behaviours, and gender stereotypes potentially decrease sensitivity to identification (Bargiela et al., 2016; Urbaniak & D’Amico, 2024). For example, girls with equivalent levels of autistic characteristics to boys still need to demonstrate more difficulties in order to receive an autism diagnosis (Duvekot et al., 2017; Dworzynski et al., 2012). Additional barriers include prohibitive costs and wait times to receive documentation. In a study with disabled students in eastern Canada, members of minoritized groups, including older students, international students, and students from lower economic social groups, reported facing more barriers to navigating and securing accommodations (Bruce, 2020).

Research indicates that autistic university students are at increased risk of failure with “high rates of academic and non-academic difficulties but low usage of supports” (Anderson et al., 2018, p. 615), with high rates of discontinuation (Cage & Howes, 2020). Access staff and administrators in Canadian universities report a lack of funding, knowledgeable staff and institutional support as barriers to supporting autistic students (Coombes et al., 2023), and only 6% of publicly-funded postsecondary institutions in Canada have autism-specific supports for students indicated on their websites (Ames et al., 2022).

Framed in critical disability, Tremain (2005) suggests that disability is not just a medical condition but also a socially constructed experience; recognizing the lived realities of disabled individuals can shift research and policy away from remedial or corrective measures toward more empowering and equitable approaches. Critical autism studies, an interdisciplinary field of inquiry founded and led by autistic people that draws on critical disability studies, further centres autistic identity, embodied knowledge, and lived experience alongside disability justice to advance the emancipation of autistic people (Milton & Ryan, 2023). Critical autism studies extends the critique found in critical disability studies by interrogating how autism is socially constructed (O’Dell et al., 2016). It continues to do so through the lens of the social model of disability, shifting the emphasis from perceived individual limitations to the ways in which society disables and marginalizes autistic individuals.

Informed by collaborations with autistic students, and through a lens of critical autism studies, this study seeks to co-construct knowledge of personal, lived experiences of Canadian autistic students, to explore the following questions:

1. How do autistic university students in Canada navigate access, including both formal accommodations and informal strategies? 2. What guidance and insights do autistic university students offer to other autistic students entering higher education, particularly around disclosure, self-advocacy, and navigating neurotypical systems?

Methods

Participants and Recruitment

Ten autistic students participated in the study. Inclusion criteria were that they were enrolled in a Canadian university at the time of the interviews (November/December 2024) and that they identified as autistic. To prevent the possibility of accidental disclosure, the participants are not presented with individual profiles. Instead, the demographics of the group of participants as a whole is presented as prose.

Participants ranged in age from 22 to 46. Seven participants were in their 20s, one in their 30s, and two in their 40s. Nine participants identified as white, and one identified as not white. Eight of the participants identified as nonbinary, agender, or genderqueer, including the two transgender individuals. The remaining two participants identified as cisgender women. Nine participants identified as 2SLGBTQI+ and one identified as heterosexual. Nine participants had been clinically diagnosed as autistic, and one participant was self-diagnosed with a clinical diagnosis of ADHD. In fact, eight of the 10 identified as having ADD/ADHD, and all participants identified having other disabilities in addition to autism, such as mental health conditions, pain-related disabilities, and mobility/flexibility disabilities. All the participants used and preferred identify-first language (e.g., autistic person), or the phrase "on the spectrum."

Three participants were enrolled in undergraduate studies and seven in graduate studies. All the graduate students completed their undergraduate degrees in Canada. All participants were registered as full-time. All participants were eligible for accommodations with their institution but two were not registered, and therefore not using formal accommodations. One participant was registered as an international student, two were studying out of province, and eight were studying in-province. Universities ranged in size from approximately 2,000 undergraduate students up to 60,000 with most in the mid-range.

Institutional Review Board (IRB) ethics approval was obtained prior to recruitment. Participants were recruited via social media, namely closed or private Facebook groups for neurodivergent and autistic students, to widen geographical reach while attempting to maintain privacy. All participants gave full informed consent before completing an online survey and opted-in to complete a follow-up interview. They were informed that they could withdraw at any point up until data analysis. Eight participants chose their own pseudonyms, and two were assigned names. Participants were compensated $50 CAN for their time which included the interview as well as member checking.

Procedure

The interview questions were developed following a review of the literature. Topics included demographics, language preferences, how they chose their programs and institutions, experiences of accommodations and disclosure, and advice for current or future undergraduate students. The semi-structured, active interviews were conducted to acknowledge participants as credible authorities on their own experiences. This approach valued their insights while also recognizing the interviewer's role in collaboratively co-constructing knowledge given her own lived experience as an autistic student. Thus, resisting a single portrait of experience but rather as mosaic of diverse and shared knowledge produced through the interaction between the researcher and participants where knowledge is not extracted but negotiated in context and where interviews often unfolded more like collaborative conversations than formal question-and-answer sessions (Holstein & Gubrium, 2011). These interviews took place over Zoom due to participants being located across Canada, but with the benefit of them being comfortable in their own homes. The participants received the interview questions in advance by email. Each interview was approximately one hour, with the option of breaks, and was recorded. There was the option to not use cameras, to reduce fatigue from normative eye contact; however, none of the participants chose this option. Real-time closed captions and the live transcript were also available to participants during the online interview. After the interview, each participant validated their transcript and had the option to change their responses by adding, removing, or revising any of their answers.

Positionality

Tension arise as researchers are both insiders and outsiders, given we are always "members of some groups and, sometimes derivatively, not of others; occupants of certain statuses which thereby exclude us from occupying other cognate statuses" (Merton, 1972, p. 22). The first author is an autistic doctoral student. A benefit of being an insider to the research domain was that she has a deep understanding of the group's experiences. In addition, being openly autistic helped create a relational intimacy where the participants felt safe to share stories on their experiences. However, the unequal power dynamics which may exist between researchers and participants are not necessarily mitigated by a researcher's autistic identity. Being a student may, in-part, have mitigated some of the power differential between the interviewer and interviewees. As an immigrant to Canada, she was also positioned as an outsider in key ways. Unlike the participants, she did not complete her undergraduate studies in Canada and therefore lacked first-hand familiarity with the specific cultural, academic, and institutional norms that shape Canadian undergraduate life. As a result, participants had to explain or contextualize aspects of their undergraduate experience during the interview.

Analysis

Lived experience of disability has important implications for both generating and analyzing data (Kerschbaum & Price, 2017). An inductive approach to data analysis was used, following Braun and Clarke's (2019) approach to reflexive thematic analysis. This approach was chosen because the aim of the study was to understand the challenges and successes of autistic students, as they experience them within the higher education system in Canada and allowed for engagement with both individual meaning-making and broader systemic influences. The interview transcripts were generated by the Zoom recording during the interviews. They were then manually verified and saved in Microsoft Word for coding. Data were anonymized, with most participants choosing their own pseudonym for analysis and reporting. Those who did not choose a pseudonym were assigned a gender neutral name. The transcripts were closely read multiple times and coded line by line with initial codes generated as new concepts or ideas. The codes were then refined iteratively and manually on a visual map to identify overlapping and intersecting codes. The first author's positionality as an autistic researcher informed, but did not determine, the analysis, highlighting how reflexivity can surface structural mechanisms embedded in individual narratives. Through iterative, interpretive engagement with the data, the analysis revealed themes that articulate how real institutional structures intersect with individual agency and identity.

Results

The themes identified were grouped into experiences accessing support, navigating negotiation, and self-accommodation.

Accessing Support Services for Disabled Students

Some claim towards autistic identity is required in order to access accommodations. When describing their language preference, everyone preferred identity-first language or "on the spectrum." Participant Alex explained identity-first language encompassed "the way that I act and express myself and navigate through the world." Whereas Julien described a preference for "on the spectrum" as this wording allowed for an expression of complexity because "all of our experiences are really, really diverse." But most participants did not feel very strongly about their language preference, sharing that they found most people are well-intentioned and, as noted by Avery, that understanding of autism is also changing with "neurodiversity, autism, and disability more in the public eye."

The range of accommodations and supports that the participants received was wide given all of them identified as having other disabilities in addition to autism. Each institution also had different requirements for "proof" and different mechanisms to decide on the allocation of provisions. For example, some participants reported institutions require a full diagnostic report from a neuropsychologist while others accepted a letter from a general practitioner. Once approved for accommodations, levels of transparency varied with some institutions providing a menu of common supports to choose from, while others required the student to name what they want and why, without guidance. Experiences ranged from very supportive to very negative, but ultimately, the participants did recommend accessing accommodations if available.

It’s the Opposite of Transparent

Positively, participants described feeling supported and that the services were “well managed, and that the staff are “well-intentioned.” But participants did not find the process of getting accommodations easy, and described it as an “ordeal” and that it “needs to be streamlined.” They also described frustrations with the lack of “transparency” and wait times. In addition, those diagnosed in adulthood who did not have an Individualized Education Plan (IEP) in elementary or secondary school were not used to navigating the accommodations process or self-advocating and lacked the awareness of the types of supports that might be available.

> Going through high school without any accommodations and then getting them later, the ones I have, have been helpful, but if they won't tell me what's available, then it's difficult for me to know what might be helpful (Jo).

However, negative experiences were also prevalent. Beck described having a disabled access advisor who was a great advocate, but when he went on sick leave Beck was never informed that they had been assigned a new advisor, which led to delays and not getting the necessary accommodations for an exam.

I Took One Look at Their Eligibility Requirements…

Not everyone used their access office. Reasons varied from the official diagnosis cost being prohibitive, concerns of future discrimination, and thinking it would not be helpful.

> I find in adulthood it's kind of useless. It's more of a risk than anything else. I feel at this point it's more like a bullseye on my medical file that I'm not particularly interested in managing (Blake).

Accommodations only being accessible for diagnosed students was described as gatekeeping and "literally an accommodation issue."

> I took one look at their eligibility requirements and then gave up. I should have advocated for myself more but I immediately knew that I did not have the paperwork that they wanted (Julien).

Participants also had preconceived notions about the services available from their access centres, based on what they had heard from others, which was not always accurate. Avery had heard "terrible stories" and decided not to apply for accommodations in their undergraduate studies.

> I felt like "Oh, well, it's not for me. I don't need that. It's not going to be able to benefit me at all." But that was just a misconception I had about the resources available (Jo).

I Had a Lot Prejudice to Unpack

Key advice from participants about accessing accommodations included being willing to ask for help. Participants described being strong students in secondary school and having to be independent, but leaving it too late to get help resulting in burnout. Participants also grappled with feelings of whether or not they were disabled enough to use the services provided describing their own prejudices that they needed to unpack, particularly those who had received their diagnosis as an adult.

> I just didn't feel comfortable with centre's student support group because I was like, "Why am I here?" Everyone in that room had more pronounced visible disability than I did. I had so much unlearning to do about autism (Julien).

Once You Are Over That Hurdle

But ultimately, those using the services often found it useful, albeit frustrating, having to reapply each year, or even each semester as Alex describes with sarcasm.

> It's just such a process that it feels intimidating. But once you're over that initial hurdle, it's not too bad... I need to go out of my way to reapply for them every year. I suppose just as a safeguard in case I suddenly stop being autistic over the summer (Alex).

Participants described having to threaten to copy ("cc") their accommodations advisor on emails before instructors would implement supports, which they would prefer to not have to do, but did feel that they had the accommodations office to "fall back on" for support.

Negotiating Accommodations with Instructors

The negotiation of accommodations directly with instructors again elicited mixed results and had varying consequences. Communication barriers were central to some of these negative experiences.

I Find it Really Difficult to Navigate Conversations

Participants’ feelings about disclosure were complex. While disclosure is not required, and some universities cautioned against it, some did feel the need to justify the need for an accommodation. Others avoided the conversation altogether due to stigmatization.

> I find it really difficult to navigate conversations where I'm asking about accommodations or discussing things related to my disability because I don't feel comfortable disclosing like that I am autistic or that it is ADHD … autism is more stigmatized but I feel like there are stereotypes for ADHD too (Jo)

Others would disclose mental health conditions because it felt like a safer, less stigmatized way to explain the challenges they were facing. But many participants expressed concerns about autism in particular being more stigmatized. They feared repercussions such as lower grades, inappropriate feedback, and being infantilized.

> I just knew how my professors felt about these things. I was just like, “Oh, hell no, I'm not telling them I'm autistic. Absolutely not” … because of the stigma, I always keep it to just health, mental health (Julien).

But some participants, particularly with hindsight, have regretted not disclosing their autism. Particularly in situations that were created by misunderstands grounded in the double empathy problem.

That was a Process of About a Week and a Half

Positively, Beck described a negotiation with an instructor where the timed quizzes where impractical for not just them but for the whole class. Students were running out of time. The solution was more time for all students which helped the whole class, making it more accessible for everyone. Beck also had positive experiences of "being allowed to do what I want," in part because they were at a small university, with small class sizes where learning was already more tailored to individual needs.

More negatively, participants described the labour required to negotiate as being tiring and time consuming. For Alex, it was a case of multiple emails back and forth and a physical meeting over a week and a half, just to be able to use a laptop in class to take notes. Other participants also avoid conversations all together, fearing the repercussions.

> I have a fear of professors not liking me or noticing them treating me differently after advocating for my accommodations to be met (Jo).

It's Not That I Don't Want to do Group Work

In some cases the negotiation fails, and students have to withdraw from a class if accommodations can't be met. In Lilah's case the instructor did not seem to understand the challenge of group work that autistic people experience and was unable or unwilling to accommodate them.

> It's not that I don't want to do group work. I can't. It's that if someone doesn't like me for some obscure reason, there is nothing I can do to bridge that because I am autistic and sometimes people just don't get you. So I had to explain that to people and actually had to drop that course (Lilah).

Communication in general appeared to be an unsurprising challenge. More than one participant described experiences where speaking directly or asking questions for clarification were interpreted as trying to "cheat" or as a challenge to authority. People such as TAs also found them rude or disrespectful when they were in fact just seeking to understand.

> I would go and see my profs to try to understand a mistake on an exam or I would try to understand comments. I found that that was when things always went askew because it was interpreted as arguing (Lua).

With hindsight, participants such as Beck shared that if an autistic student feels misunderstood "it's probably a communication barrier and we can work it out" (Beck). Others, such as Lua, recommended finding ways to work outside the IEP model and "negotiate directly with the prof." Lastly, participants' advice to students negotiating accommodations was, in the word of Alex, to be "nice, but firm."

Self-Accommodation and Other Advice

In the interviews, we asked about experiences of accommodations and disclosure. We also probed the participants' wider university experiences. Participants provided advice to incoming and current undergraduate students.

Despite challenges, participants still advised student to access supports even if it "feels weird about taking advantage of those resources", as Jo described, and to unlearn their biases against accessing support.

> I've always felt very entitled to them. I have problems. I deserve this. I haven't had an issue with that, but I know people do. So do your best to unlearn that and just use what you need (Robin).

You Need to Accommodate Yourself First

Just as there is no universal Canadian university experience, there is no universal autistic experience or advice, but self-accommodation was a recurring theme where students described creating their own access solutions or “the hacks disabled people utilize for navigating and altering inaccessible worlds” (Hamraie & Fritsch, 2019, p. 3).

> Each person's autism influences their autistic experience and our needs aren't all the same. For me, beyond accommodations that could be offered, there were accommodations that I learned to offer myself (Julien).

Examples included gathering examples of accommodations from other students when attending a university that was not forthcoming with the options available. Another participant, Beck, suggested if a student was struggling with attending class to go anyway, even if only to spend the time answering emails or working on other tasks, therefore ensuring their attendance was noted, and in the hope that their motivation might change allowing them to focus on class. They also advised using AI-generated templates to reply to emails on difficult executive functioning days.

When choosing a university or a program, the advice was to visit and see if it would be a good fit. Participants described the positives and negatives of both large and small universities with large and small class sizes. Some preferred the anonymity of the larger experiences, others enjoyed knowing all their peers and instructors well. Participants encouraged their peers to find out what worked for them.

> You need to accommodate yourself first, like finding what kind of lectures work for you, what kind of professors work for you (Beck).

Other common advice was to not force yourself into things that are not right for you, from your class subjects to your wider university experience.

> Don't force yourself to try and do something if it's really not your jam because you're going to hate it. For autistic people, trying to force themselves to do things that they just can't get into... you're just setting yourself up for misery (Avery).

Self-Advocacy is Going to be One of the Skills That Benefits the Most

Participants spoke of self-advocacy being a very important skill to develop, particularly if it had always been done for them, such as with an Individualized Education Plan (IEP) in school. Later diagnosed participants, who did not have an IEP at school, had to learn these skills while at university. Participants described it as "exhausting" but important. Self-advocacy requires an awareness of your needs, which takes time to develop, but it is an important step to take.

> It's okay not to know what you need. But to start figuring it out. Start to name it. Learn to trust yourself and learn to say what you need and not rely on somebody else to tell you what you need or to read what you need (Lua).

Find Your Communities When You Are Ready

Many participants described the importance of finding people, even just one person, to share with and to talk about how being autistic impacts your university experience in order to protect their mental health. The disability advocacy space was considered to be important, but not always possible.

> I don't know like if I would give this advice to everybody but definitely for me getting involved with the disability advocacy space helped immensely (Jo).

Participants described community that might be elsewhere in the city, rather than on campus depending on the disability culture of the campus, through the queer community, or through structured activities targeting more introverted students.

> There’s quite a few autistic people in university, but it's hard to find the other people that are hiding. You will eventually find them. I put a lot of pressure on myself that first week to go out and do stuff so I'd have friends but, I would have found them eventually. I don't think that I had to worry about it as much as I did (Robin).

Although community was highlighted as valuable, participants emphasized that new students should not feel compelled to establish friendships or a sense of belonging immediately, given the significant transitions they are navigating.

Discussion

Although most participants avoided direct disclosure, some had positively embraced their autistic and disabled identities. This activism is reported to empower students to advocate for themselves and others, contributing to the breakdown of stereotypes and biases surrounding disability (Moriña & Biagiotti, 2022). A positive autistic identity is clearly important, but not necessarily possible for everyone. Several participants reported feeling uncomfortable with the conversations required to negotiate their accommodations with their instructors. Students are often hesitant or unprepared to embrace a disability identity framework at university, but they have limited options to secure accommodations and support effectively (Bruce, 2020). Disclosure can lead to positive outcomes. When autistic individuals mask their behaviour, it can be related to higher rates of depression. Autism acceptance, from both external sources and self-acceptance, reduces rates of both depression and stress (Cage et al., 2018).

A study with autistic students in the UK found a recurring theme of needing to take personal responsibility for educating their instructors about their disabilities, therefore being forced not only to disclose but also become extra-visible (MacLeod et al., 2018). This visibility concerned participants who were highly aware of the possible negative repercussions of disclosure, including not being liked or infantilized. Studies have demonstrated the negative snap judgements people often make of autistic people (Sasson et al., 2017), in addition to misinformed ideas that autistic people do not feel empathy or do not understand the internal states of others (Heasman & Gillespie, 2018). Autistic students are facing real discrimination and this underscores the need for better understanding and awareness raising in the university context.

There is an increasing awareness that autistic students require additional and tailored support (Anderson et al., 2022). Supportive social relationships with staff such as academic advisors, internship advisors, psychologists, and guidance counsellors also contribute to a sense of belonging for autistic students. These relationships are reported to be most beneficial when they involved listening to autistic students and providing individualized advice over longer durations (Pesonen et al., 2020). Many participants in this study have not experienced consistent longer term access support relationships from their university access centres’ staff. Accessibility staff and administrators in Canada acknowledge the obstacles to providing autism-specific supports such as a need for more funding, knowledgeable staff, and institutional support (Coombs et al., 2023). In addition, access was not accessible nor transparent for the participants as they reported challenges with providing the necessary documentation “proof” as well as a lack of upfront information on what supports might be available. While some universities were open about what was available and might be appropriate to support students, others expected the students to negotiate with no information beyond their previous IEP. Access offices and support services provide reasonable accommodations as long as they do not cause undue hardship to the institutions as mandated by policy and laws—policies are designed to protect the university from disabled students (Dolmage, 2017). NEADS’s *Environmental Scan of Institutional Policies* (2018), reported that institutional policies around accessibility and accommodation vary widely and are implemented inconsistently across Canada. Similarly, the participants in this study had wide ranging experiences.

The experiences of participants with preconceived notions of not being disabled enough to use their access centre is also echoed in the literature. The stigma associated with disability leads to non-disclosure as disabled students experience faculty and peers seeing them as lesser (Moriña, 2022). The potential for negative experiences grounded in stigma and discrimination is a serious social and attitudinal barrier. A study in Australia with autistic students found that the most common reason for delaying disclosure was the desire to try university on their own, without external support (Anderson et al., 2018). Students with invisible disabilities in another study in the USA reported they had accepted and developed strategies to address their learning challenges (Kreider et al., 2015), referring to their desire to succeed without academic accommodations whenever possible, which could be framed as internalized ableism (Moriña, 2022). The participants in Kreider et al.'s study did not identify with a disability identity partly because it is "invisible." They did not really believe in their disability status or found it difficult to accept that they needed accommodations to continue to be academically successful. This highlights the need for education around who access centres actually serve, as well as larger questions of how to destigmatize autism to autistics and allistics (non-autistic people) alike.

The self-advocacy burden faced by the participants reiterates the need to shift from accommodations to wider access. Disabled students report that accommodation-related tasks can create a "sometimes devastating impact of additional labour" (Bruce, 2020, p. 429), when students with disabilities are already managing the additional cognitive load associated with navigating their lived experience with a disability both inside and outside the educational setting (NEADS, 2018). This self-advocacy also places the burden on students as individuals. Self-advocacy is understood to be an essential skill for disabled students in their transition from high school to university (Bruce, 2020), and also from university to the workplace. Disability and the need for accommodation are constructed as a problem at the individual level rather than an opportunity to reimagine inclusion and access. Dolmage (2017) described individualized and reactive accommodations as a game of Whack-a-Mole where no long-lasting changes are made to pedagogy or university culture, thus upholding existing barriers and hindering change.

Mismatched communication styles left participants struggling to negotiate with instructors and misunderstood by teaching assistants and peers. This disconnect can be explained by the Double Empathy problem (Milton, 2012): communication difficulties between autistic and non-autistic individuals arise from a mutual lack of understanding because both groups have different ways of perceiving and interpreting social interactions. In fact, communication between autistic people is typically no less smooth than between allistic people (Crompton et al., 2020), demonstrating the “problem” is not how autistic people communicate, but the differences in communication between allistic and autistic people. Because allistic instructors are likely unaware of this difference, it is important to educate faculty, staff, and students on campus about the communication differences as a crucial step toward fostering a more inclusive environment.

Participants shared the importance of self-accommodation as a strategy for navigating university life. At the individual level, disabled students need a range of personal competences to succeed in university, including self-awareness, self-efficacy, and self-esteem, which can be developed through training (Moriña & Biagiotti, 2022). Autistic students in the study by Pesonen et al. (2020), recognized their individual characteristics and preferences as strengths, which in turn increased their involvement with other students who shared similar interests. This self-awareness and self-esteem ultimately supported their sense of belonging (Pesonen et al., 2020). In addition, the use of self-accommodation highlights not just an individual coping mechanism, but a resistant practice that challenges institutional inaccessibility. Rather than passive recipients of (inadequate) support, the autistic students in this study are shown to be active agents reconfiguring their environments. This contributes to disability studies by shifting the frame from individualized "success strategies" to acts of reclaiming autonomy and agency in hostile systems.

Participants emphasized the need to “find your community,” which extends beyond friendship into belonging, cultural affirmation, and resistance to stigma. This reframes support from being service-based to identity-affirming, with potential to inform campus planning, disability cultural centres, and peer-led networks. Participants’ expressions of needing to “find their community” echo Piepzna-Samarasinha’s (2022) claim that disabled community is often missing not because it doesn’t exist, but because it has been intentionally fractured by ableism and isolation.

Implications For Research

Future research should further conceptualize self-accommodation not only as a survival strategy but as a form of micro-resistance and praxis within inaccessible systems. Investigating how these student-developed strategies circulate informally could advance our understanding of access as community-generated infrastructure. Additional future inquiry might examine how academic and social miscommunications emerge in higher education, and how institutions can operationalize neurodivergent communication frameworks in curriculum and policy. Developing and evaluating neurodiversity-affirming pedagogies, informed by autistic and other neurodivergent voices, offers a promising direction, particularly when grounded in Universal Design for Learning (UDL). Lastly, the significance participants placed on disability community as a site of cultural affirmation highlights a need to explore the structural role of autistic community in shaping identity, wellbeing, and academic persistence. Researchers might study how community formation among autistic students functions both as mutual aid and as a response to systemic institutional neglect. Aligning with calls from disability justice literature, future work could examine how universities might foster cultural spaces, such as disability cultural centres, that normalize disabled existence and affirm neurodivergent ways of being.

Limitations

While the participants of this study are from across Canada, not all provinces and territories are represented. In additional, the group is not racially diverse. This is problematic as autistic people of colour are already under-represented in diagnosis and therefore have less access to accommodations, and are under-represented in autism research (Harrison et al., 2017). In addition, the study did not include any participants who are currently Augmentative and Alternative Communication (AAC) users, who again are under-represented in autism research. Recruitment via social media, namely Facebook, also limited representation to a self-selecting group of students. Lastly, there is a high discontinuation rate for autistic students. While some of the participants had taken medical leave or transferred to a different institution, they have continued in their studies. Absent are the lived experiences of former students who discontinued their studies.

Conclusion

As the number of autistic adults entering higher education continues to rise, it is essential to gain insight into their experiences. First-hand accounts of their lived experiences at university can highlight areas that need improvement and help identify key priorities for future research and policy development. The results shed light on the topics of disclosure and use of accommodations, alongside recommendations for self-accommodations from the research participants. While many autistic individuals view autism as neutral, they find society often attaches negative meaning and stigma (Botha et al., 2021). This stigma and a perceived lack of wider autism understanding can hinder access to necessary accommodations. Participants also reported problems with the lack of transparency navigating accommodations, and the undue burden of self-advocacy in the form of cognitive load, resistance and power imbalance. In addition, mis-matched communication styles, explained by Milton's Double Empathy problem (Milton, 2012), where different neurotypes communicate differently but the burden is on the neurominority to change their communication, left students struggling to negotiate with instructors, and misunderstood by teaching assistants and peers. Raising awareness of autism across faculty, staff, and peers on campus is a crucial step toward fostering a more inclusive environment.

Additionally, participants emphasized the importance of self-accommodation and community as a strategy for navigating university life more effectively by building their own access outside of the institutional systems that are currently not accommodating them, and are slow to change. By integrating self-accommodation practices alongside institutional support, autistic students can better manage the demands of higher education, reducing unnecessary stress and barriers, and ultimately increasing their ability to thrive, persist, and complete their studies with greater well-being and success. Autistic students are not only seeking peer relationships, they are seeking mirrors and models for what an empowered disabled life can look like. Their search is not just for emotional support, but for cultural affirmation and disabled futures they can imagine themselves into. Lastly, autistic people have historically lacked epistemic authority necessitating the ability or access to contribute to knowledge formation on autism. Both lived experience and autistic-led research such as this study are potentially important contributions to the field. In conclusion, this paper, aims to sheds new light on the experiences of autistic students in the Canadian university context.

This research was supported by funding from the Faculty of Arts and Science and the School of Health at Concordia University.

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