

Examining the Strengths, Experiences, and Needs of Canadian Post-Secondary Students with  
Autism Spectrum Disorder: A Pilot Study

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Submitted in partial fulfillment  
of the requirements for the degree of  
Master of Arts in Applied Disability Studies with a Specialization in Applied Behavior Analysis

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## Abstract

Post-secondary students with a diagnosis of Autism Spectrum Disorder (ASD) represent an underserved and underrepresented population in post-secondary environments and research. A study in the United Kingdom found that post-secondary students with ASD reported a higher frequency of thoughts about withdrawing from studies and difficulties with adjustment compared to other students. However, Canadian research exploring the experiences and needs of Autistic post-secondary students is limited. Additionally, few studies have reported the perspectives of post-secondary students on the autism spectrum directly. The purpose of this study was to develop and pilot a survey designed to examine the self-reported strengths, experiences, and needs of Canadian post-secondary students with ASD. The development of this survey was guided by steering committee members with relevant lived experiences. Pilot testing was conducted with a sample of 13 individuals who self-identified with ASD and had recently attended or were currently attending college or university in Ontario. This thesis was divided into three separate studies. Study 1 described an effective application of a participatory action research approach to develop a survey. Study 2 reported preliminary findings following pilot testing of the survey. Strengths reported by participants were mainly academic, while areas of limitation included social challenges and barriers within the post-secondary environment. Participants generally reported positive sentiments regarding services accessed. Study 3 described the process for gathering feedback for survey revision from pilot participants, which highlighted a preference for quantitative questions and provided suggestions for revision for future iterations of the survey. Recommendations for future research were discussed.

*Keywords:* post-secondary, PAR, participatory action, Autistic, ASD, mixed methods

## **Preface**

Given the content and format of this thesis, it is important to identify and acknowledge the potential impact of my lived experiences relevant to this subject. In addition to my experiences as an undergraduate and graduate student in Ontario, I have also worked in the post-secondary student services sector for close to a decade. In those roles, I have connected with many students who identified with the autism spectrum. The impact of those experiences contributed to my decision to attend this program and focus on this thesis topic in particular, as I firmly believe that Canadian campuses would benefit from best practices and recommendations regarding ways to better meet the needs of students on the autism spectrum.

### **Acknowledgement**

First and foremost, I would like to thank Dr. Rosemary Condillac for your support, encouragement, and insights throughout this process and my time at Brock University.

This project could not have occurred without the input and efforts of the SEN-CAPS Steering Committee. Thank you for providing your time, sharing your expertise, and contributing to the collegial and collaborative atmosphere of our work together. Your words of encouragement and the energy present during all of our meetings helped me to finish this thesis. The project would not have been the same without the unique and important contributions offered by each individual member.

To the members of my thesis committee, Dr. Priscilla Burnham Riosa, Dr. Nicole Luke, and Dr. Carly McMorris, thank you for offering your time, perspectives, and expertise to guide the development of this thesis, support my growth as a scientist-practitioner, and enhance the project overall.

I would also like to express my appreciation for the time and relationally acquired knowledge contributed by the individuals who completed the pilot survey and provided feedback for revision and next steps. This was invaluable in the process of exploring this important topic.

I am also grateful to the members of the Condillac lab who assisted with testing of the web-based survey and verification of thematic analysis results.

Last, but certainly not least, I want to thank my partner, family, and friends for their encouragement, support, and understanding during this time of intense focus.

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Examining the Strengths, Experiences, and Needs of Canadian Post-Secondary Students with  
Autism Spectrum Disorder: A Pilot Study

**Chapter 1: Introduction**

Post-secondary students with Autism Spectrum Disorder (ASD) are underserved and underrepresented in the post-secondary environment. Recent research found that students with ASD in the United Kingdom (UK) reported a higher frequency of difficulties related to adjustment and thoughts about withdrawing when compared to other students (Gurbuz, Hanley, & Riby, 2019). Research focused on the experiences of Autistic post-secondary students in the United States (US) found significant differences in physical and mental health, academic performance, and social relationships when compared to disabled and non-disabled peers (McLeod, Meanwell, & Hawbaker, 2019). Further, research focused on enrollment found that individuals on the autism spectrum in the US were less likely to enrol in post-secondary studies than individuals in “visible” and “invisible” disability groups (Wei, Yu, Shattuck, McCracken, & Blackorby, 2014). Research conducted in both the US and Belgium suggested that enhancing post-secondary supports to better meet the needs of post-secondary students with ASD may increase retention and success (e.g., Barnhill, 2016; Van Hees, Moyson, & Roeyers, 2015).

A comprehensive understanding of the strengths, experiences, and needs of Autistic post-secondary students is an essential first step to inform the development of supports and services. However, there are few studies that examined the experiences of post-secondary students on the autism spectrum, and even fewer that acquired this information from the students’ perspectives. Further, Canadian research in this area is limited. This thesis focused on the development and revision of a survey using a participatory action research (PAR) approach. This survey was used to gather information directly from students with ASD.

The current thesis was conducted to support the aims of a larger research project<sup>1</sup> which intended to explore the strengths, experiences, and needs of Canadian Autistic post-secondary students. The aims of the current thesis were achieved through developing, testing, and refining a survey using a PAR approach. This intentional and evidence-based process resulted in the development of a relevant and effective survey. Following further revision, this survey will be administered to a larger sample of Canadian post-secondary students on the autism spectrum to support the development of a comprehensive understanding of relevant strengths, experiences, and needs. The findings of this survey will guide the development of recommendations for policy and best practices relevant to post-secondary students with ASD.

This thesis was divided into three separate studies exploring three related and distinct components of the larger research project. The first study explored the use of a PAR approach to develop a survey exploring the strengths, experiences, and needs of Canadian Autistic post-secondary students. The second study reported on the preliminary findings produced by pilot testing of the survey developed in the first study. The third study focused on the feedback for revision of the survey provided by the aforementioned pilot participants.

## **Literature Review**

This chapter features a review of the relevant literature to describe the empirical support and rationale for the current thesis. This review of the literature provided an overview of the current state of the relevant research, highlighted pertinent findings, and identified gaps in the literature. Following a review of the literature relevant to the experiences of post-secondary

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<sup>1</sup> This thesis was carried out as part of the first Phase of the Strengths, Experiences, and Needs of Canadian Autistic Post-Secondary Students (SEN-CAPS) research project. We appreciate the funding we have received from the Faculty of Social Sciences for the Council Research in the Social Sciences (CRISS) Research Award.

students with ASD and to the research project at large, a summary of the purpose and aims of this thesis and the larger research project were provided.

**Autism spectrum disorder.** Autism is a neurodevelopmental condition that has been diagnosed in an estimated one in 66 children and youth in Canada (Public Health Agency of Canada, 2018). A 2018 report estimated that 90% of children and youth who were diagnosed with ASD in Canada received their diagnosis by the age of 12. Recent reports of ASD prevalence in Canada and the United States have found that the prevalence of ASD has been increasing across the last two decades (Centers for Disease Control and Prevention, 2020; (Public Health Agency of Canada, 2018). The American Psychiatric Association (APA; 2018) describes ASD as “a complex developmental condition that involves persistent challenges in social interaction, speech and nonverbal communication, and restricted/repetitive behaviors” (para. 1) with symptoms and severity differing across individuals. These differences in symptoms and severity currently all fall under the umbrella of ASD. However, many individuals identify more strongly with terms other than ASD, such as Autistic, on the autism spectrum, or neurodiverse. To align with and respect the varied preferences for terminology, the words Autistic, on the autism spectrum, with ASD will be used interchangeably within this thesis to refer to individuals identifying with ASD. Person-first and identity-first language will also be used.

**Post-secondary education.** Post-secondary education programs aim to prepare an individual for employment in a specific field, resulting in improved outcomes for employability and earnings. Experiences in the post-secondary environment can also support skill development (e.g., interpersonal, financial, time-management, and critical thinking) relevant to career readiness (Western Michigan University, 2020). Attending post-secondary studies can also

provide opportunities for social and personal experiences, such as meeting new people or living independently in a new city.

*Autistic post-secondary students.* Despite increases in prevalence of ASD in Canada and enrolment in post-secondary studies in Ontario (Alcorn MacKay, 2010; Public Health Agency of Canada, 2018), Autistic individuals have historically been underserved and underrepresented on post-secondary campuses (McLeod et al., 2019; Wei et al., 2014). Not only are individuals on the autism spectrum less likely than their peers experiencing other disabilities to enrol in post-secondary studies (Roux, Shattuck, Rast, Rava, & Anderson, 2015; Wei et al., 2013), Autistic post-secondary students also reported a higher frequency of thoughts about withdrawing from studies and difficulties with adjustment when compared to post-secondary students overall (Gurbuz, et al., 2019). Specifically, an American longitudinal study focused on youth with ASD found that 36% of participants had attended post-secondary studies within the first five years after completing high school; those who attended were enrolling at a lower rate than participants with a learning disability or speech-language impairment (Roux et al., 2015). A recent study conducted by McLeod, Meanwell, and Hawbaker (2019) compared responses to an online survey from Autistic college students, college students with other disabilities, and non-disabled college students in the US ( $N = 3073$ ). The authors found that students with ASD reported significantly worse outcomes in the areas of health and mental health, academic performance, and social relationships and bullying as compared to non-disabled students, while few significant differences were reported between students on the autism spectrum and students reporting other disabilities. Enhancing post-secondary supports and services to better meet the needs of post-secondary students with ASD may increase Autistic student retention and program completion (Barnhill, 2016; Van Hees, Moyson, & Roeyers, 2015).

Research focusing on Autistic post-secondary students explored relevant areas of need, supports available, and related outcomes (e.g., Barnhill, 2016; Cai & Richdale, 2016; Cullen, 2015; Knott & Taylor, 2014; LeGary, 2017; Ness, 2013; Shmulsky, Gobbo, & Donahue, 2015). However, the existing research has focused primarily on the experiences of individuals studying in the US and UK (e.g., Madriaga, 2010; Vincent et al., 2017; Weiss & Rohland, 2015; White, Elias, et al., 2016). Most studies have sought the perspectives of staff, faculty, and family members (e.g., Barnhill 2016; Morrison, Sansosti, & Hadley, 2009; Smith, 2007). However, research examining this topic area primarily or solely through others' perspectives may not fully capture the multifaceted first-hand experiences of post-secondary students with ASD.

Few studies have examined experiences directly and exclusively from the students' perspectives (see Table 1-1). Existing studies often included a small sample size (range 7–66). Research which included the perspectives of students on the autism spectrum identified areas of need including social skills (e.g., developing and maintaining friendships), executive functioning skills (e.g., time management), mental health concerns (e.g., anxiety), independent living skills (e.g., navigating transportation), and academic skills (e.g., navigating group work; Cullen, 2015; Jackson et al., 2018; Van Hees et al., 2015; Vincent et al., 2017). It is notable that most studies focus on current undergraduate students or graduates. Further, no empirical studies focusing on the experiences of individuals with ASD who were enrolled in, but did not complete their post-secondary studies, were encountered through the review of the literature. A study conducted by Gelbar and colleagues (2015) also identified the lack of inclusion of Autistic individuals who stopped attending post-secondary studies as a gap in the literature.



Table 1-1

*Research Focusing on the Experiences of Autistic Post-Secondary Students with Autistic Post-Secondary Student Participants*

Publication Year	Authors	Country	Participants			Participatory Action Research
			Sample Size	Education Level	Method	
2018	Anderson et al.	Australia	48	Current undergraduate and graduate	Online questionnaire	No
2018	Berry	US	7	Current community college	In-person semi-structured interview	No
2018	Jackson et al.	US, Canada, and UK	56	Current undergraduate and community college	Online survey	No
2018	Sarrett	US	66	Vocational, undergraduate and graduate, graduation status not specified	Online survey and online focus group	Yes
2017	Casement, Carpio de los Pinos, and Forrester-Jones	Spain and UK	9	Current post-secondary	In-person life history interview	No
2017	LeGary	US	10	Current undergraduate	Written survey and in-person semi-structured interview	No
2017	Vincent et al.	UK	7	Current undergraduate or undergraduate completed	Written critical autobiography	Yes
2015	Cox et al.	US	9	Current high school, vocational	In-person semi-	No

				school, community college, and graduate	structured interview	
2015	Cullen	US	24	Current undergraduate	Online questionnaire, online and in- person interviews and in-person focus group	No
2015	Gelbar et al.	US	35	Current undergraduate or undergraduate completed	Online survey	No
2015	Van Hees et al.	Belgium	23	Current post- secondary	In-person semi- structured interview	No

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Two studies were identified where the methodology closely aligned with a PAR approach in which Autistic individuals were included as members of the research team. One study included Autistic individuals in all stages of the action inquiry process, while one study included Autistic individuals in obtaining feedback regarding a survey to be administered to Autistic post-secondary students. However, only one, a study conducted by Vincent and colleagues (2017) was described by the authors as PAR and included Autistic individuals in all stages of the action inquiry process. This study examined only the experiences of the student co-researchers. The second study, conducted by Sarrett (2018), included Autistic individuals in survey development but did not consult Autistic individuals in data analysis. In a PAR approach, it is essential to include individuals with lived experience in all stages of the action inquiry process.

The study conducted by Vincent and colleagues (2017) used a PAR approach to explore the perspectives of six current Autistic undergraduate students and one recent graduate in the

UK. Participants, identified in the study as co-researchers, provided written critical autobiographies exploring their experiences in relation to key issues, challenges, and successes in the post-secondary education context. Five of the seven co-researchers participated in thematic analysis in collaboration with a “neurotypical” co-facilitator. All co-researchers then participated in the verification of the themes identified. This study found that substantial challenges and barriers exist for Autistic post-secondary students. Themes identified included a sense of difference, social interactions, responding to change and independence, and fear versus reality. Study limitations included the small sample size and emphasis on the experiences of the co-researchers, which may not be representative of all Autistic post-secondary students. Following their participation, the co-researchers anecdotally reported a positive and personal impact from their experience of collective action. The co-researchers also reported that they felt empowered and had taken opportunities to support the development of more socially just pedagogies.

A recent study conducted by Sarrett (2018) explored the experiences of Autistic post-secondary students related to accommodation supports and sought recommendations using a survey and focus groups. The research team included two Autistic self-advocates, one academic not involved in research focusing on ASD, and one non-Autistic, non-academic individual who provided feedback regarding survey length, flow, phrasing, comprehension, and accessibility, after which revisions were made. The refined survey was completed by 66 adults on the autism spectrum across the US who reported attending post-secondary studies; 31 also participated in online focus groups. Levels of education reported by the participants included college, university, community college, vocational school, graduate studies, and medical school. Participants reported mixed levels of satisfaction with accommodations; many participants noted that accommodations focused primarily on academic needs. Participants also reported that needs

related to sensory and social concerns were often not addressed through accommodations. Recommendations for social accommodations included disability support groups, peer mentorship, and mediators trained in neurodiversity. Recommendations for sensory accommodations were neurodiverse spaces including available quiet spaces, options for sensory time, and physical spaces for social gatherings that consider sensory needs. The author highlighted recommendations endorsed by post-secondary students with ASD for increased involvement of Autistic individuals in program development and increased Autism awareness on campus for staff, faculty, and peers. A limitation identified in this study was possible selection bias effects in the recruitment process, as individuals who chose to participate may have already been more involved in neurodiversity and individuals who did not participate may have been unable to participate due to disability-related reasons.

Two additional studies stood out in the review of the literature due to the relatively large sample sizes and broad exploration of student needs (described below). These studies informed the conceptualization of topic areas relevant to post-secondary students on the autism spectrum, providing a basis for discussion using a PAR approach. Both studies used online questionnaires to assess needs, highlighting this methodology as an effective means of data collection. However, these studies were not without limitations as neither included Autistic individuals in the research team or interpretation of the findings. Further, both studies focused on populations of post-secondary students with ASD registered with campus accessibility supports and therefore were not necessarily representative of the experiences of all Autistic post-secondary students.

A study conducted by Anderson and colleagues (2018) explored the perspectives of 48 Autistic post-secondary students attending eight universities in Australia using an online questionnaire. This study sought to determine the demographic characteristics, self-reported

strengths and weaknesses, and experiences with supports and services of post-secondary learners with ASD registered with accessibility services on campus. This study found that 44% of respondents delayed starting university for at least one year. Self-reported strengths identified by respondents were mostly academic, such as attention to detail, while self-reported weaknesses were generally non-academic, such as anxiety symptoms. Participants reported high levels of satisfaction with supports and services, with academic supports identified as most helpful and non-academic supports identified as least helpful. However, respondents reported that they did not access many supports and services, and those who did access supports and services often only did so occasionally. Respondents who delayed disclosure of their disability status identified reasons including a lack of knowledge of services, a lack of support needs, and fear of stigmatization. Although respondents who did and did not delay disclosure both reported loneliness, anxiety, and depression, respondents who delayed disclosure were more likely to withdraw and reported lower satisfaction with supports and their university experience. Identified limitations of this study included the low rate of completion and lack of inclusion of individuals on the autism spectrum not connected with accessibility supports. The authors recommended that research and practice should explore the development of programs to support Autistic post-secondary students and identified a need for future research outside of the US and UK.

An American study conducted by Cullen (2015) explored the needs of post-secondary students with ASD through naturalistic inquiry ( $N = 24$ ). Three options for data collection were offered to accommodate participants: online questionnaires, online or in-person individual interviews, and in-person focus groups. This study examined the self-reported social needs and experiences of Autistic students in meeting those needs. This study found that needs identified

by students generally fell within three categories: social needs, academic needs, and daily living needs. Social needs included meeting new people and social communication skills. Academic needs related to academic group work and social elements in the classroom. Daily living needs included navigational skills such as taking the bus, as well as organization and prioritization skills. It was reported by 15 of 33 participants (45.45%) that social needs were met by classmates or school-related activities, while 11 participants (33.33%) reported needs were met by family. A small but not quantified proportion identified needs were met through social media. A primary implication of this study was that success for post-secondary students with ASD could be enhanced by activities and services to support social interactions. The lack of inclusion of Autistic individuals not connected with disability services was identified as a limitation. A recommendation for future directions identified by the author was further exploration of social media as a medium that may benefit students, researchers, and service providers.

*Canadian context.* Considerable differences exist between the Canadian and American post-secondary environments (Fullick, 2015; Heath, 2015; Johnson Hess, 2018; Robson, Anisef, Brown, & Nagaoka, 2019). Specifically, differences exist in supports available within and outside of the post-secondary settings (e.g., publicly funded health and mental health services). Although research to date explored supports, needs, and outcomes relevant to post-secondary students with ASD, a comprehensive evaluation of the experiences of Autistic post-secondary students in the unique Canadian context is needed to inform the development of supports, services, and recommendations. Anderson and colleagues (2017) identified that there was a particular need for quantitative surveys with larger samples of post-secondary students on the autism spectrum outside of the US and UK.

The review of the literature located four empirical studies which reported on the experiences of Canadian post-secondary students on the autism spectrum. Three of the studies focused on a specific mentorship program for students on the autism spectrum. Namely, Ames, McMorris, Alli, and Bebko (2016) conducted a program evaluation focused on a mentorship program for 23 Autistic undergraduate university students, while Ncube, Shaikh, Ames, McMorris and Bebko (2019) explored social skills development in a sample of 23 undergraduate students with ASD enrolled in the same mentorship program. Evaluation of the mentorship program found that participants were satisfied and achieved their identified goals (Ames et al., 2016). Ncube and colleagues (2019) found that participants did not report increases in social support or quality of friendships during their first year in the program. Additionally, McMorris and colleagues (2019) explored experiences related to mental health service access of 45 university undergraduate students on the autism spectrum and found that the support needs of participants were not being met and that multiple barriers impacted service access (McMorris et al., 2019). The fourth study identified explored how mentorship was experienced by 9 Autistic university student mentees enrolled in a mentorship program for university students with ASD using interviews and found a core theme described as a mentee-centered approach (Roberts & Birmingham, 2017).

Additional research articles which related to the Canadian post-secondary environment and autism were also identified. Specifically, although a survey examining self-reported experiences and needs included four participants on the autism spectrum who attended post-secondary studies in Canada, the survey was also completed by individuals who attended post-secondary studies in the US ( $n = 49$ ) and UK ( $n = 3$ ), results were not differentiated by country (Jackson, Hart, Brown & Volkmar, 2018). A study conducted by Trevisan and Birmingham

(2016) compared the relationship between college adjustment and Autistic traits in a sample of 153 Canadian undergraduate students but did not include any participants who disclosed a diagnosis of ASD. Importantly, research confirmed that the number of students with ASD enrolled in post-secondary studies was growing in Ontario; a recent survey of secondary and post-secondary institutions estimated that 1,100 Autistic students would enrol in post-secondary studies between 2009 and 2011 (Alcorn MacKay, 2010). This report indicated that enrolment was expected to continue to increase over time. Therefore, increasing the need for specialized supports relevant to learners on the autism spectrum in the post-secondary setting in Ontario.

**Participatory action research process.** Few studies have sought the perspectives of Autistic students in the research process. “Nothing about us, without us” is an essential perspective when studying the needs of individuals who identify with a specific disability group. Although the origin of this phrase is not known for certain, James I. Charlton (1998) credited two disability rights activists in South Africa, Michael Masutha and William Rowland, who identified that they had first heard the phrase at a disability rights conference in Eastern Europe. This phrase embodies the empowerment that grew through the disability rights movement and contributed to a fundamental shift in how the needs of disabled people were explored and addressed. This sentiment was echoed by Cameron and Moore (2013) in their summary of the discipline of Disability Studies, which emerged in the UK in the 1980s through the work of disabled scholar Mike Oliver, in the statement “it has remained essential within Disability Studies that the voices of disabled people must always be enlisted in the building of ideas, theories, and practices” (p. 38). Autistics for Autistics, a Canadian self-advocacy group, also emphasizes the importance of direct advocacy and input from individuals on the autism spectrum in policies and processes that affect them (Autistics for Autistics, 2019).



Research using a PAR approach has been widely recognized as an effective approach to facilitate engagement of individuals who were previously underrepresented or not at all consulted in research (e.g., Dudgeon, Scrine, Cox, & Walker, 2017; Glassman & Erdem, 2014; Kindon, Pain, & Kesby, 2007). This orientation aims to empower at the individual and community level, as well as to support social change (Baum, MacDougall, & Smith, 2006; Glassman & Erdem, 2014; Kindon, Pain, & Kesby, 2007; Wallerstein & Berstein, 1994). This is achieved through supporting the genuine participation of individuals with relationally acquired knowledge, leveraging their strengths and unique perspectives. By definition, PAR includes research of a systematic nature, which incorporates the active involvement of individuals with lived experience in all phases of the action inquiry process (Chevalier & Buckles, 2019). Literature exploring applications of PAR have recognized the opportunity presented by this approach to mitigate imbalances of power often present between researchers and community members through collaboration in the development, implementation, and dissemination of research (e.g., Flicker et al., 2008; Glass & Newman, 2015; Louie, 2016).

Inclusion of the individuals with relevant lived experiences is imperative in research using a PAR approach. The studies conducted by Sarrett (2018) and Vincent and colleagues (2017) discussed above provided examples of participatory action in research focusing on specific topic areas. Specifically, the study conducted by Sarrett (2018) included two Autistic self-advocates in survey review but did not consult individuals on the autism spectrum in the analysis of the results. The critical autobiography methodology utilized by Vincent et al. (2017) would not be feasible with a large and representative sample size of Canadian post-secondary students with ASD. In conducting research using a PAR approach, while it is important to consider the benefits and limitations of previous research, it is also important to consult the

broader empirical literature to guide collaborative decisions related to research development and design.

*Mixed methods.* A mixed methods approach has been used effectively in PAR (e.g., Maxam, 2012; McCalman et al., 2017; Sarrett, 2018). The origin of mixing methods in research has been credited to Jick (1979). The process of mixing methods was developed to provide a method for researchers to reach consensus across qualitative and quantitative methods in social sciences research (Ostlund, Kidd, Wengstrom, Rowa-Dewar, 2011). Mixed methods research allows researchers to examine topics thoroughly, leveraging the strengths of both qualitative and quantitative methods (Klassen, Creswell, Plano Clark, Smith, & Meissner, 2012). This approach allows researchers to develop a comprehensive understanding of a topic through identifying patterns and exploring phenomena.

*Qualitative research.* The use of qualitative methods facilitates the thorough exploration of subject matter within the real-world context, supporting increased applicability of the research findings, particularly when exploring subject matter that may be complex and interrelated (Yardley & Bishop, 2017). Strengths of qualitative research include the ability to conduct research with a relatively small sample and to explore the subject matter in detail (Creswell & Plano Clark, 2011). Research conducted using qualitative methods allows researchers to analyze outliers rarely explored in quantitative research, highlighting individual and varied experiences that may not otherwise be elucidated. Although a common criticism of qualitative methods highlighted in the research literature relates to the impact of preconceptions or biases of the research team, these concerns are mitigated when data are analyzed using systematic and well-documented qualitative methodologies (Malterud, 2001).

One method of systematic qualitative analysis is thematic analysis. Braun and Clarke (2006) described specific guidelines to support the deliberate and rigorous application of thematic analysis including: (a) familiarizing yourself with your data; (b) generating initial codes; (c) searching for themes; (d) reviewing themes; (e) defining and naming themes; and (f) producing the report. Thematic analysis may also allow for social interpretations and unanticipated insights. Thematic analysis can be particularly useful in the context of PAR as it is accessible to researchers with a range of qualitative research experiences as is common in PAR.

*Quantitative research.* The use of quantitative methods allows researchers to efficiently and effectively analyze large data sets to facilitate categorization, comparison, and exploration of causal relationships (Yardley & Bishop, 2017). Strengths of quantitative methods also include high levels of internal validity as procedures are precise and easily replicable. It is important to note that the strengths of quantitative methods only apply when certain minimum requirements are met, such as a sample size, particularly if certain statistical analyses are to be conducted. However, in circumstances where the sample size is not sufficiently large or representative of the population, researchers may rely on alternative methods, such as integrating an existing measure that references an established norm. Including an existing standardized instrument when conducting quantitative research is also generally more efficient and effective than creating a new instrument to measure a specific variable or examine an area of interest (Black, 2005).

*Research design.* A synergistic partnership-based fully integrated mixed methods research framework recognizes the iterative process required in a multi-phase research project and emphasizes collaboration with stakeholders in research using a participatory approach (Tashakkori & Teddlie, 2010). This design is highly flexible and conducive to research conducted in multiple phases across an extended period of time using a PAR approach. This

design was first proposed by the authors and described as a framework which “incorporates the synergistic framework of Hall and Howard with professional collaborative and stakeholder participatory approaches to achieve pragmatic and transformative goals as well as scientific goals” (p. 322). The authors identified pragmatism as the theoretical paradigm most often associated with arguments to support combining qualitative and quantitative methods in research. However, this approach is not without challenges. The integration of qualitative and quantitative methods has been identified as a potential source of tension and difficulty in the development of research through a PAR approach (Sendall, McCosker, Brodie, Hill, & Crane, 2018).

In mixing methods, it is imperative that research is designed and conducted intentionally and effectively to produce clear and meaningful results (Tashakkori & Teddlie, 2010). Creswell and Plano Clark (2011) identified that the development of research design should be grounded in pragmatism with consideration of what works in the real-world context; to determine what works, decisions must be evidence-based. However, the lack of empirical evidence to guide decisions related to mixed methods design has been identified as a gap in the literature (e.g., Covell, Sidani, & Ritchie, 2012; Friborg & Rosenvinge, 2013).

One area that should be considered in mixed methods research design is the relative weighting or priority of qualitative and quantitative data collection. These decisions can be guided by the research question, theoretical drive, and other practical considerations, such as resources and the influence of others involved in the research (Creswell & Plano Clark, 2011). A pragmatic theoretical orientation allows for equal or unequal weighting depending on which will best address the research question. A convergent parallel design is when quantitative and qualitative data are collected in the same phase of research, while an explanatory design prioritizes and first collects quantitative data, and an exploratory design prioritizes and first

collects qualitative data. When this weighting or prioritization does not fit within the existing design or draws on elements from several designs, it may be described as a dynamic approach.

When developing mixed methods research, researchers should consider the subject matter. Certain topics may be better suited to exploration using qualitative or quantitative methods, particularly when the subject matter may be considered sensitive. For example, in a study comparing responses to open-ended and closed-ended questions from a subsample of adults in Ontario who reported drinking at least five drinks in one sitting in the previous year, Ivis, Bondy, and Adlaf (1997) found that participants reported higher rates of alcohol use with closed-ended questions and higher rates of missing data with open-ended questions. Response accuracy can also be impacted. A study exploring the collection of demographic information from Canadian general internists reported more missing data, but fewer inaccurate responses, when questions were presented in an open-ended versus closed-ended format (Griffith, Cook, Guyatt, & Charles, 1999). Exploring a topic using both qualitative and quantitative methods can facilitate a more thorough exploration. A study focusing on the stressors and strains experienced by graduate students reported that the findings supported the combination of qualitative and quantitative methods in research examining stressors as these methods provided different information (Mazzola, Walker, Shockley, & Spector, 2011).

When mixing methods, researchers must also consider is the sequence in which qualitative and quantitative questions are presented, particularly when questions focus on similar or highly related topics. This temporal relationship is described in the research literature as timing, where qualitative and quantitative data collection can occur concurrently in the same phase or sequential phases in research (Creswell & Plano Clark, 2011). Previous research argued that open-ended questions may be impacted by previously presented closed-ended questions and

that therefore, open-ended questions on similar subjects should be presented first (e.g., Morse, 1991). However, a more recent study compared sequencing effects of closed and open-ended questions in surveys and interviews of 50 Canadian nurses and reported that the order of presentation did not significantly impact responding (Covell, Sidani, & Ritchie, 2012).

The manner in which qualitative and quantitative strands are mixed is also important to consider in mixed methods research. This mixing is often described as the stage of integration (Creswell & Plano Clark, 2011). This integration, or mixing, can occur during design, data collection, analysis, or interpretation. When integration occurs during interpretation, both strands are collected and analyzed separately, then combined and compared in the discussion.

Researchers must ensure that item-level details are not neglected in the development of effective and high-quality research. For instance, the level of detail provided in survey questions can impact response quality. Research focusing on responses to open-ended questions in online surveys found that including information that clarified expectations for response quality and length improved response quality (Smyth, Dillman, Christian, & McBride, 2009). Additionally, in providing guidance for survey methodology in the social sciences, Gideon (2012) highlighted the importance of question phrasing, specifically avoiding double-barreled, double-negative, leading, loaded, or repetitive questions. Questions should be brief, focused, and precise to support accurate responding and reduce the probability of non-response.

Researchers must also consider the format through which their questions are presented to participants. When examining the perspectives of a large and geographically distributed population, an online survey is a practical approach which provides a large amount of empirical data which may be more generalizable (Kelley, Clark, Brown, & Sitzia, 2003; Lefever, Dal, & Matthiasdottir, 2007). A study conducted by McCalman and colleagues (2017) used a PAR

approach to design and pilot a survey focusing on the resilience and risk for self-harm of Indigenous secondary students in Australia. In this study, students, education staff, healthcare providers, and researchers worked collaboratively to develop, refine, and pilot a survey.

### **Significance**

Post-secondary success may have a substantial positive impact for Autistic adults. Specifically, improved life outcomes have been associated with post-secondary education for Autistic individuals (Hendrickson, Carson, Woods-Groves, Mendenhall, & Scheidecker, 2013). Therefore, it is imperative to build a better understanding of ways to address the unique needs of post-secondary students with ASD and support student success (Taylor, 2005). This is particularly important given the dearth of research focusing on students on the autism spectrum at the college, undergraduate, and graduate levels, especially within the Canadian context.

This project focused on several areas where further exploration is warranted. Specifically, this project explored the perspectives of all Autistic post-secondary students, including those not connected with disability services and those not currently registered in studies. Research exploring the experiences of individuals on the autism spectrum who were previously enrolled in but did not complete post-secondary studies represents a substantial gap in the literature (Gelbar et al., 2015). Previous studies identified the overrepresentation of individuals connected to disability services on campus as a limitation (e.g., Anderson et al., 2018; Cullen, 2015; Sarrett, 2018). This project began to address these gaps in the literature.

The unique approach of this project not only addressed existing limitations but expanded on the very limited body of research using a PAR approach by including post-secondary students with ASD and other individuals with relationally acquired knowledge within this context. This thesis combined the methodological strengths of existing literature to provide a thorough and

relevant exploration of the experiences of Autistic post-secondary students. This was enhanced through direction provided by individuals with relevant lived experience, an underutilized approach (e.g., Anderson et al., 2018; Cullen, 2015; Gelbar et al., 2015; Jackson et al., 2018). This project built on the existing PAR literature by including individuals on the autism spectrum in all stages of the action inquiry process, representative of a quintessential PAR approach.

In examining the post-secondary experiences of Canadian Autistic post-secondary students, it is important to explore individual strengths and limitations, as well as supports and potential gaps in service to inform recommendations and guide best practices to effectively support student success. The development of this measure which will facilitate a comprehensive understanding of the needs of post-secondary students with ASD in Ontario is an essential first step. Working alongside people on the autism spectrum enhanced the relevance and validity of the project.

### **Purpose**

The purpose of this thesis was to use a PAR approach to develop and refine a survey to gather information from the perspective of post-secondary students with ASD regarding their needs. The exploratory survey pilot provided preliminary findings regarding the strengths, experiences, and needs of Canadian Autistic post-secondary students. The feedback on the pilot survey provided evidence for revisions of this survey in preparation for an Ontario and pan-Canadian administration. This thesis was divided into three studies: the first focusing on survey development using a PAR approach, the second reporting on the preliminary results of the exploratory pilot, and the third exploring the survey feedback provided by the pilot participants.

### **Research Questions**

The overarching research questions of each of the three studies were as follows:



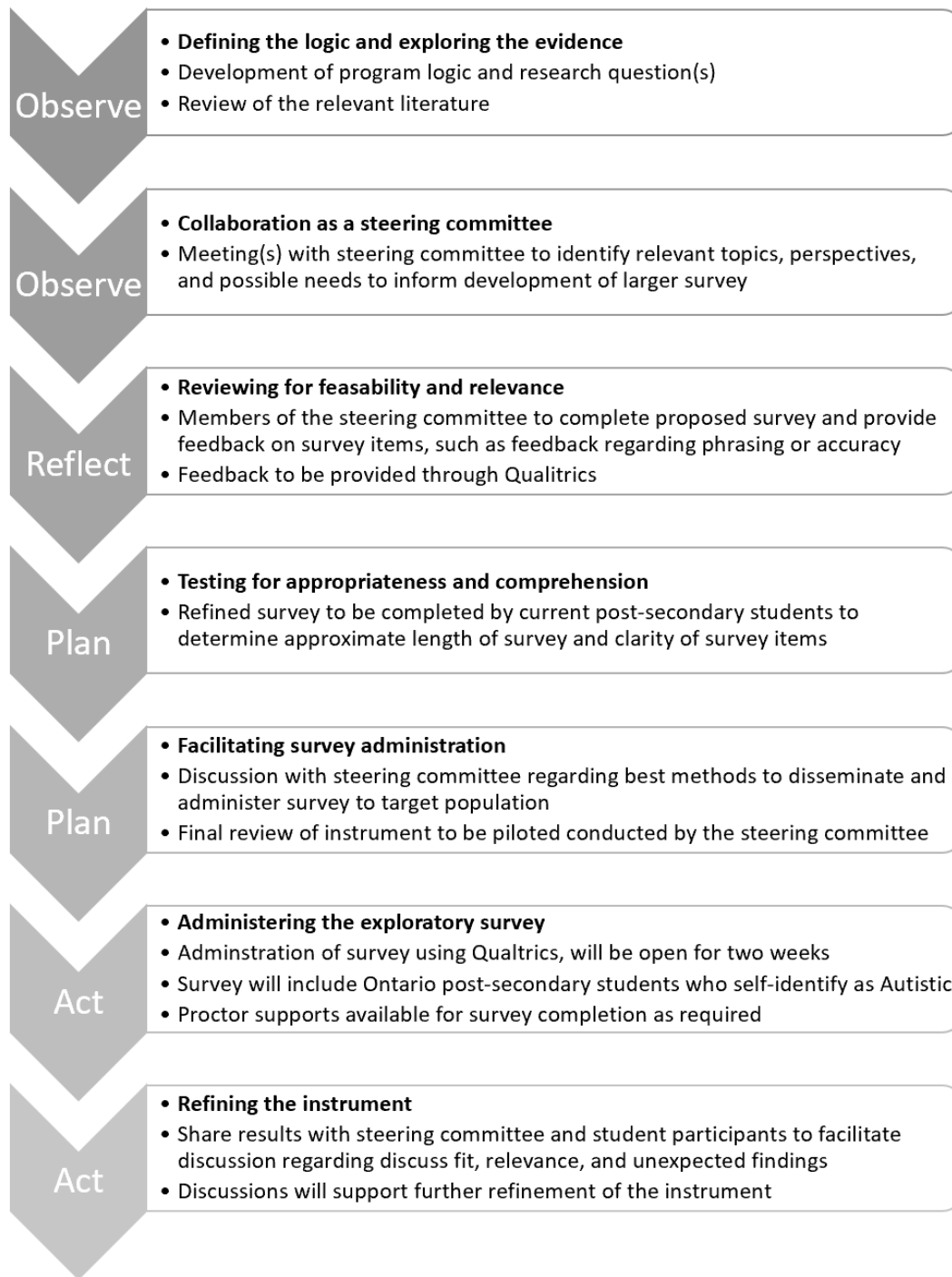
1. Can a PAR approach be used to effectively develop a draft survey to examine the strengths, experiences and needs of Canadian Autistic post-secondary students?
2. What were the preliminary findings of the draft survey developed to examine the self-reported strengths, experiences, and needs of Canadian post-secondary students on the autism spectrum?
3. What were the strengths and weaknesses of the draft survey developed using a participatory approach as reported by Canadian post-secondary students with ASD?

## **Method**

The methodology of this thesis was guided by and adapted from a PAR process described by McCalman et al. (2017), outlined in Figure 1-1.

**Research design.** Overarchingly, the research described in this thesis most closely aligned with a synergistic partnership-based fully integrated mixed methods research framework due to the iterative process of survey development driven by the collaboration as a steering committee as emphasized in research using a PAR approach (Tashakkori & Teddlie, 2010).

**Procedure.** The larger project included seven phases and was adapted from a study conducted by McCalman and colleagues (2017). The phases included: (a) defining the logic and exploring the evidence; (b) collaboration as a steering committee; (c) reviewing for feasibility and relevance; (d) testing for appropriateness and comprehension; (e) facilitating survey administration; (f) administering the exploratory survey; and (g) refining the instrument (see Figure 1). The implementation of phases a through c are described in Study 1, while the implementation of phase d is described in study 2 and study 3. Phases e through g will be completed as part of the larger project, but not discussed in this thesis.



Adapted from McCalman et al., 2017.

Figure 1-1. Procedure for development, refining, and piloting of needs assessment survey.

## Chapter 2: Study 1

This study focused on the development of a survey measure using a PAR approach. The core features of a successful PAR process, as well as strengths and challenges of using a PAR approach are discussed. The topic areas and aspects related to survey format identified as important, as well as the final format and content of the survey are reported.

### Introduction

It is imperative that research exploring the needs and experiences of a specific group consult individuals with lived experiences who identify as members of that group. This approach not only ensures a fulsome examination of the subject matter but lends credibility to the findings.

**Participatory action research.** There are several examples of a PAR approach being used effectively in research focusing on post-secondary students on the autism spectrum (e.g., Hotez et al., 2018; MacLeod, 2010; Maxam, 2012; Vincent et al., 2017). Although limited, research has focused on the strengths, experiences, and needs of Autistic post-secondary students in general (e.g., Maxam, 2012; Vincent et al., 2017). Notably, dissertation research conducted by Maxam (2012) used a PAR approach to collaborate with faculty and Autistic students in the US to examine needs, challenges, and recommendations relevant to post-secondary students with ASD. Much of the existing research has focused on the development of specific specialized supports. Research conducted in the UK by MacLeod (2010) focused on the development of an online peer support network for Autistic post-secondary students using a PAR approach, which was successful in fostering peer-to-peer support. The study conducted by Hotez et al. (2018) explored the development and revision of a summer transition program for Autistic individuals entering college in the US which was guided by feedback provided by program participants and synthesized by one participant with ASD. Providing preliminary support for the feasibility of

PAR with Autistic students in program development and implementation was described as a strength of this study.

Research using a PAR approach should aim to optimize results. For example, technology can reduce response effort and allow for increased flexibility in participation. A recent systematic review focusing on technology use in youth-led PAR in the US and Portugal conducted by Gibbs, Kornbluh, Marinkovic, Bell, and Ozer (2020) found that technology was effectively used to connect individuals in various geographic locations and was often used to gather data in PAR. This review reported that Facebook was used most commonly; videoconferencing, email, personalized mapping applications, and social media were also used to engage individuals in research. Similar to all high-quality research, research using a PAR approach requires time and resources from all parties. The allocation of sufficient time was identified by MacLeod (2010) as an important consideration for PAR with post-secondary students on the autism spectrum.

***Mixed methods.*** Mixed methods research combines strengths of quantitative and qualitative methods, allowing researchers to develop a comprehensive understanding of a topic through identifying patterns and exploring phenomena (Klassen, Creswell, Plano Clark, Smith, & Meissner, 2012). When the research method is refined and emerges during the research process, it is described as an emergent mixed methods design (Schoonenboom & Johnson, 2017).

In conducting qualitative research, an important consideration often identified in the literature is the potential preconceptions of the research team, formed through lived experiences, which may impact the research process (e.g., Malterud, 2001; Smith & Noble, 2014). While the unique vantage point of researchers is central to a PAR approach, the lens through which qualitative research is conducted is objective and reflexive (Malterud, 2001). When conducting qualitative analysis, researchers attend systematically to and create sufficient distance from their

individual lived experiences to mitigate the impact of any preconceptions. In research using a PAR approach, a researcher's individual lived experiences are often situated within the data focused on lived experiences and relationally acquired knowledge relevant to the subject matter. The process of analysis of qualitative data is further supported by the application of a "thorough, well-prepared, and well-documented analysis" (Malterud, 2001, p. 486).

**Survey design.** A survey is a method that facilitates the combination of qualitative and quantitative items in mixed methods research. In designing an effective survey there are many aspects to consider in order to maximize the quality and quantity of data collected. In addition to content, it is important to consider format. Decisions should be guided by the priorities of the research team; for example, a web-based survey provides a cost-effective option that is accessible across geographical regions, while an in-person focus group or interview is more resource-intensive, but may allow researchers to be responsive to participants' during data collection. Web-based surveys have been associated with higher rates of self-disclosure. One recent study compared self-reports provided by Australian youth on a telephone interview and web-based survey (Milton et al., 2017). This study reported higher rates of self-disclosure on sensitive items with the web-based survey; this finding was particularly pronounced for participants who identified as male.

### **Purpose**

The purpose of this study was to use a PAR approach to develop a draft survey examining the strengths, experiences, and needs of Canadian Autistic post-secondary students in preparation for a survey pilot.

### **Research Questions**

This study explores the following research questions:

1. What were the core features of the PAR process which supported the successful development of a survey measure?
2. What topic areas were identified as important and relevant to the survey by the steering committee?
3. What technological features and approaches were recommended by the steering committee to enhance acceptability and inclusion?
4. What was the final format and content of the survey developed by the steering committee for pilot testing?

## **Method**

This study used a synergistic and partnership-based PAR approach to design and develop a survey.

**Membership on the steering committee.** Consistent with a PAR approach, a steering committee of seven individuals with lived experiences related to the post-secondary experiences of students with ASD was formed. Eight individuals were initially contacted regarding membership on the steering committee. One person was unable to participate and declined the invitation, while another person declined the invitation and recommended another representative from their organization. This group was large enough to facilitate representation of relevant and diverse lived experiences but was small enough to allow each individual to engage actively in discussions. The steering committee included the principal investigator (PI) and principal student investigator (PSI; the author) who provided required oversight and managed logistics and administrative support, but otherwise functioned as contributing members of the committee. Steering committee members included recent graduates, family members of individuals on the autism spectrum, representatives from community organizations, university faculty, and post-

secondary student services staff including representation from counselling, accessibility, and career services. Many members belonged to more than one stakeholder group (as disclosed on their personal information and confidentiality form), but there was not a requirement for members to self-identify to the other members of the committee in order to avoid perceived tokenism or pressure on any member to provide a specific perspective during discussions as a steering committee. The steering committee included representation from the Greater Toronto Area, Niagara Region, and National Capital Region of Ontario, Canada.

**Recruitment of steering committee members.** Potential additional steering committee members were contacted directly by the principal investigator or principal student investigator. No open call was made as specific organizations and individuals were selected for recruitment to support the development of a small group of individuals with diverse lived experiences. Draft terms of reference and a letter of invitation were shared with individuals who agreed to consider participation. Steering committee members completed a confidentiality agreement and were given an opportunity to ask questions and have them answered to their satisfaction. This agreement also included space for steering committee members to share personal preferences (e.g., pronouns), relevant lived experiences, and preferences related to the meeting time and format. From this point forward, references to the steering committee will include the PI and PSI.

**Procedure.** The steering committee's decision-making process was collective and collaborative, with conclusions driven by the preferences and perspectives of the steering committee as a whole. The date and time of each meeting was selected by the steering committee. Steering committee members suggested topics of discussion before each meeting. An agenda and related materials were compiled and available before each meeting. Detailed notes were completed during each meeting; notes were summarized in meeting minutes and used to

guide project work between meetings. Minutes, slides, and other relevant materials were shared via email after each meeting. Meeting minutes were shared through a link to a Google Doc (Google LLC, 2020), which allowed steering committee members to make additions and changes to the minutes as necessary.

The first meeting of the steering committee focused on establishing parameters and procedures for the collaborative PAR process. Meeting topics included the introduction of the research project, discussion of the project vision, and guidelines for privacy and confidentiality. During this meeting, the steering committee finalized the terms of reference and identified preferred methods of information-sharing. In all meetings, the screen-sharing feature and other technological supports were leveraged to provide both verbal and written access to the material being discussed to ensure that the material was accessible.

***Survey development.*** Survey development described in this study included four of the seven phases adapted from the study conducted by McCalman and colleagues (2017). This study focused on: (a) literature review and development of program logic; (b) collaboration as a steering committee; (c) reviewing for feasibility and relevance; and (d) testing for appropriateness and comprehension.

***Defining the logic and exploring the evidence.*** An expansive review of the literature was conducted and summarized in Chapter One. A thorough search was conducted using the Supersearch function through the Brock University Library, PsycINFO database, ProQuest Dissertations and Theses Global database, and Google Scholar to identify relevant studies focusing on the experiences of Autistic post-secondary students. Search terms used focused on student status, such as college, undergraduate, graduate, post-secondary, and higher education, diagnostic terms, such as *autis\** and ASD, areas of interest, such as needs, outcomes, supports



and services, and study methodology, such as PAR, surveys, interviews, and focus groups. The search results were reviewed manually to assess the fit and appropriateness of each research article with the research topic. Scholarly articles describing reviews of the literature and experimental research designs relevant to the experiences of Autistic post-secondary students were reviewed. Empirical studies included the perspectives of post-secondary staff and faculty, parents and significant others of Autistic post-secondary students, as well as recent and current post-secondary students on the autism spectrum.

*Collaboration as a steering committee.* The steering committee met as needed via the Lifesize Cloud Video Conferencing (Lifesize Inc., 2020). Flexibility in expectations was crucial to support the ongoing involvement of steering committee members through the duration of the project, allowing for changes and differences in the frequency and format of participation. Steering committee members contributed to the research tasks between meetings at the level that they wished to be involved. In addition, some steering committee members provided written contributions between meetings, others made their contributions during meetings, and some contributed both ways.

The steering committee discussed possible survey topics relevant to the experiences of Autistic post-secondary students to support survey development. This discussion was guided by topics identified through the review of the relevant literature. The steering committee opted to present the topic areas identified through these discussions using a mind map. All areas of importance identified were summarized in the mind map to provide a visual depiction of the relationships between the various topic areas. This mind map was developed collaboratively through screen sharing during videoconference meetings using the LiveBoard Interactive Whiteboard online application (Liveboard LLC, 2017).

Later meetings and discussions with the steering committee focused on phrasing, format, flow, and logic. These discussions focused on the mixing of methods, as well as the content and phrasing of specific questions. This discussion was further supported by a collaborative Google Doc (Google LLC, 2020) where proposed questions were shared with steering committee members for review, feedback, and revision. This review period lasted two weeks. The proposed survey questions were then entered in Microsoft Word (Microsoft Office 365 MSO, Version 2008; Microsoft Corporation, 2020), with the survey questions divided across three parts: Part A; Part B; and Part C. Following several weeks of review and feedback, questions were entered into a web-based survey using Qualtrics XM software (Qualtrics, 2020).

*Survey review for feasibility and relevance.* Members of the steering committee independently reviewed the proposed survey to assess the feasibility and relevance of individual questions and the survey overall. This review was completed across a two-week period between meetings. Several methods for providing input and feedback were available, including individual meetings by phone or videoconference or written feedback. Steering committee members provided feedback using the method that was most preferable to them. The web links for Parts A, B, and C of the survey were provided in sequence to steering committee members via email.

Instructions and information about the feedback process were shared via email and accompanied the link to access Part A. Steering committee members provided feedback directly in the survey using existing open-ended questions or by entering feedback in the text box available at the end of each survey page. Prompts were provided within the survey to solicit feedback on specific areas and questions where there had been a lack of consensus. Steering committee members used survey navigation to explore alternate paths of survey logic.

The feedback provided by steering committee members was compiled to identify potential revisions. Summarized feedback was presented back to the steering committee via videoconference. The discussion in this meeting focused on specific items or areas where feedback was contradictory. Steering committee members who were not able to attend contributed by alternate means, such as by email. Discussions continued until consensus was reached, with some notable exceptions. For areas where consensus was not reached, two sets of questions were developed: one with a qualitative emphasis and one with a quantitative emphasis to facilitate comparison and further exploration through pilot survey testing. These decisions informed additional survey revisions.

*Testing for appropriateness and comprehension.* The steering committee developed the procedure for survey testing. Topics of discussion included recruitment, administration, and analysis. Survey testing is discussed in detail in Study 3.

## **Results**

**Core features of participatory action.** Several features of the PAR approach emerged through the collaborative process of survey development.

**Inclusivity.** The steering committee included individuals with diverse lived experiences relevant to post-secondary students with ASD, such as family members and post-secondary staff who support students on the autism spectrum. The steering committee members agreed that individuals who know, love, and/or support others who had experiences with post-secondary studies and the autism spectrum also had valuable insights and perspectives, in addition to those who had attended or were attending post-secondary studies and identified with ASD.

**Voluntariness.** Steering committee members did not receive compensation for their involvement in this project. However, the employers of some steering committee members were

supportive of their involvement and allowed them to complete research activities during work hours. Additionally, the PSI benefitted from the research conducted as the focus of this thesis, an essential component of completing her Master of Arts degree.

***Collaboration.*** The decision-making process in this project was dynamic and collaborative. All steering committee members shared their thoughts, perspectives, and preferences through open and honest discussions resulting in decisions made collectively. This collegial and collaborative atmosphere was pervasive throughout all steering committee research activities.

***Flexibility.*** Participation in this project was highly flexible. Steering committee members participated in meetings and research activities on a voluntary basis that was flexible and responsive to their strengths, preferences, and availability.

***Anonymity.*** Steering committee members were not asked or obligated to disclose their personal details in connection with their lived experiences to other members of the steering committee. Although not required, many steering committee members did share personal experiences and anecdotes in support of the larger goal of the project, indicative of their comfort with the other steering committee members and the PAR process.

***Respect.*** The exploration of the lived experiences of the steering committee members often included subject matter that was difficult or considered sensitive. Differences in opinions and perspectives between steering committee members were also highlighted through this process. The steering committee members always navigated these topic areas with respect, understanding, and appreciation of the perspectives of their peers.

***Communication.*** Steering committee members identified a preference for virtual communication (i.e., email) for important information, such as meeting materials and dates. Additional prompts as needed (e.g., text messages) were also identified as helpful. Steering

committee members identified collaborative web-based applications, such as Google Docs (Google LLC, 2020), as preferable for draft documents especially, as these applications allowed steering committee members to work collaboratively in real-time and access documents at their convenience.

***Timing.*** The activities of the steering committee far exceed the initial timelines developed for the research project. Initially, the steering committee planned to conduct the survey pilot in March of 2020, which was delayed and launched closer to May 1. As of January 2021, the survey pilot was completed, and data were being compiled to support discussions with the steering committee regarding the revision of the survey as described in this thesis. Significant delays related to conducting research during the COVID-19 pandemic and recruitment-related challenges impacted this timeline. However, the steering committee also experienced challenges finding time to meet with balancing other personal and professional obligations. During steering committee meetings, the magnitude and enthusiasm of the discussions often limited the number of agenda items that could be addressed in each meeting, which further impacted the timeline for this research project. Members communicated their commitment to seeing the project through, irrespective of delays.

**Survey development.** Each phase of survey development produced a defined product, which culminated in the development of a draft survey for the project pilot.

***Defining the logic and exploring the evidence.*** Through the review of the literature focusing on the experiences of post-secondary students on the autism spectrum, 11 studies were identified which focused on the experiences of Autistic post-secondary students and included only Autistic post-secondary students in the sample. A table summarizing key methodological aspects and corresponding research findings was provided in the Introduction section.

**Collaboration as a steering committee.** The steering committee identified several terms that individuals on the autism spectrum may prefer to identify this attribute, specifically, neurodiverse, on the autism spectrum, with ASD, and Autistic. To ensure that the phrasing presented in the survey aligned with individual preferences and identity, the steering committee determined that this choice should be used to inform survey logic. Much of the discussion with the steering committee focused on identifying important topic areas to include in the survey. These topics were summarized in a mind map (Figure 2-1).

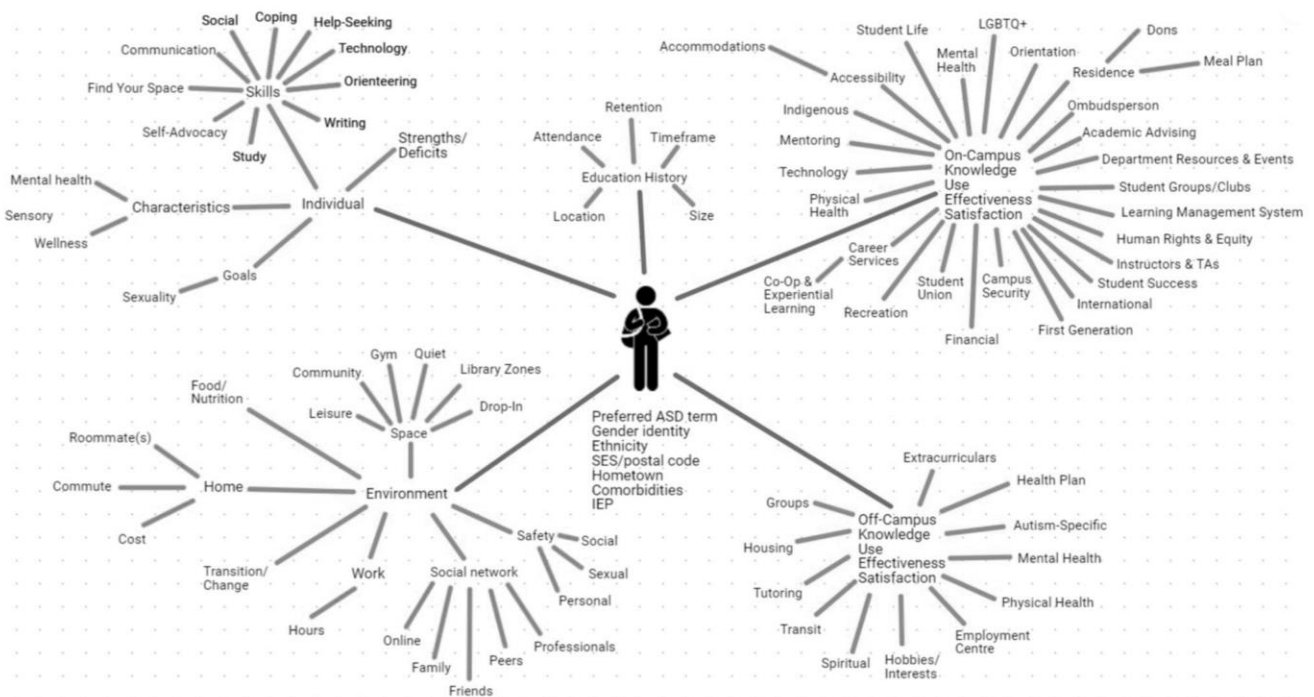


Figure 2-1. Mind map summary of areas of importance identified by the steering committee.

This mind map was referenced in discussions regarding the relative priority and the depth of examination for each topic area. The steering committee determined that on-campus service use, individual skills and strengths, and employment would be examined in the greatest detail, with a moderate emphasis on demographic characteristics, education history, and off-campus service

use. Although questions focusing on spaces, social connections, home environment, and individual goals would be included in the survey, these topic areas would not be a primary focus.

Through discussions focused on format and phrasing, the steering committee identified minimizing the time required to complete the survey and using clear and concise language as priorities. The steering committee identified a preference for open-ended questions and side-by-side matrix drop-down questions in the survey to allow for the thorough exploration of a topic area while minimizing the total number of survey questions. Examples of phrases identified by the steering committee as clear and concise language included: *comfortable*, *important to you*, *impact to you*, and *what would you like more of*.

During discussions regarding mixing methods, the steering committee did not reach a consensus on the best method for exploring several topics. Areas where consensus was not reached included on-campus service use, off-campus service use, spaces, and academic accommodations. Therefore, the steering committee developed a set of qualitative questions and a set of quantitative questions for each of those topic areas for comparison.

The list of topic areas and outcomes of discussions of question format guided the development of the survey, as well as a brief screening survey. The screening survey included 10 qualitative and quantitative questions. The survey included 246 qualitative and quantitative questions in total and was divided into three parts, with 191 items in Part A, 35 items in Part B, 20 items in Part C.

***Survey review for feasibility and relevance.*** Consensus was reached for all potential revisions during survey review. The steering committee, revised, removed, and relocated several survey items. Specifically, the steering committee revised the phrasing of questions about spaces, such as by removing the word *safe*, removed questions about previous employment, and

relocated questions asking participants to share any relevant information not addressed in the survey from the end of Part A to the end of Part C. The steering committee also revised the format of questions focusing on participant identity, specifically changing questions exploring participant creed, ethnicity, and sexuality from a defined list to open-ended text boxes to allow for a broader range of potential responses.

The steering committee also identified several general revisions as important. Specifically, the size of text boxes for all open-ended responses was increased and an option to exit the survey was included on each page. Based on suggestions provided through the review process, the steering committee also discussed adding a “not applicable” option within each row of the side-by-side matrix questions, but ultimately opted to revise the question phrasing to inform respondents that they could skip any items that did not apply to their experiences to minimize response effort.

To facilitate data collection for survey pilot feedback, Part D, the steering committee opted to add a text box after where participants could provide item-level feedback following each question in a copy of the pilot survey which would be presented in a separate survey link. It was determined that pilot participants would be instructed to utilize the table of contents feature to access specific questions. In addition, the steering committee added questions to solicit overall feedback to the end of Part D of the survey.

The revised survey was divided into four sections in preparation for the survey pilot, in addition to a screening survey. The screening survey included seven questions, while the larger survey included 190 items in Part A, 37 items in Part B, 25 items in Part C, and 7 unique items in Part D. See Table 2-1 for a summary of survey topic areas by survey part. The estimated completion time identified by Qualtrics XM software was 1 hr 12 min for Part A, 20 min for Part



B, and 19 min for Part C, for a total of 1 hr 51 min for Parts A through C. The estimated completion time for Part D was 1 hr 24 minutes.

Table 2-1

*Final Survey Flow, Content, and Primary Question Types Following Survey Review Phase*

Survey part	Content	Primary question types
Screening Survey	Eligibility	Multiple choice and short answer
	Consent	Multiple choice
Part A	Demographic characteristics	Multiple choice and open-ended
	Education status	Multiple choice
	Strengths, skills, and experiences	Rating scale and open-ended
	Experiential Learning	Multiple choice
	Employment	Multiple choice
	Previous education	Multiple choice and matrix-style
Part B	Spaces and extracurriculars	Open-ended
	Supports and services	Open-ended
	Academic accommodations	Open-ended
Part C	Spaces and extracurriculars	Matrix-style
	Supports and services	Matrix-style
	Academic accommodations	Matrix-style
	Summary	Open-ended
Part D	Part A items with feedback option	Open-ended
	Part B items with feedback option	Open-ended
	Part C items with feedback option	Open-ended
	Overall feedback	Open-ended

**Testing for appropriateness and comprehension.** The steering committee identified an online survey facilitated through Qualtrics XM software (Qualtrics, 2020) as sufficient for survey testing. Concerns about survey length and accessibility for individuals with difficulties related to reading or writing were identified as a potential barrier to access. To mitigate this concern, the steering committee determined that individualized accommodations would be available as required and could include reader or scribe support aiding in-person, over the phone, or virtually.

The steering committee also discussed procedures for recruitment and compensation. The steering committee determined that eligible participants would self-identify as Autistic or a person on the autism spectrum and have attended college or university in Ontario within the last two years. The steering committee agreed that criteria could be revised if required if the initial recruitment procedures did not result in a sufficiently large sample, such as by increasing the number of years since participants had last attended college or university. To facilitate recruitment of individuals who met the eligibility criteria and support survey completion, the steering committee decided that recruitment procedures would not be random and participants would be contacted directly by members of the steering committee. To mitigate ethical concerns related to undue influence, privacy, and confidentiality, it was determined that interested individuals would be directed to contact a dedicated email address monitored by the PSI who would be unknown to potential participants.

The steering committee determined that participants should be compensated for their time and expertise. With consideration of the hourly rate of compensation for graduate students (the highest level of education amongst the proposed survey sample) the rate of 25 dollars per hour was identified as appropriate. As the estimated time for completion for all parts of the survey was over three hours, the steering committee determined that participants should receive up to 100 dollars for participation, with 25 dollars provided contingent on completion of each survey part. In fact, one of the steering committee members was able to help secure additional funding to assist with compensation.

## Discussion

This study focused on the development of a survey using a PAR approach. It is important to consider the results in the context of the final product, the survey developed, as well as the relevant features of the PAR process.

**Core features of participatory action.** Overall, the steering committee members worked together effectively and collaboratively. Several core features of the PAR process may have contributed to this dynamic. Before beginning this process, steering committee members shared their personal pronouns, lived experiences, communication preferences, and general availability for meetings. This information was used to ensure that the group was best meeting the needs of all steering committee members. Additionally, early in the PAR process, the steering committee reviewed and refined the terms of reference. This process and the related discussions were helpful in setting expectations and guiding interactions amongst steering committee members. These discussions helped to foster a respectful and inclusive environment while mitigating any concerns regarding requirements to disclose personal information or inflexible expectations regarding participation. As participation was voluntary, it is also important to note that the intrinsic motivation of steering committee members may have positively impacted the group dynamic. This supportive and collaborative dynamic underscored all activities with the steering committee and was further exemplified by the continued involvement of the steering committee despite the presence of ongoing and additional stressors related to the COVID-19 pandemic which further delayed the research process. This active collaboration demonstrated the empowerment and mitigation of common imbalances of power in research commonly associated with a PAR approach (Kindon et al., 2007; Dudgeon et al., 2017).

There were several clear benefits of using a PAR approach in this project. Most importantly, the PAR approach enhanced the final product of this study, the survey. The PAR process resulted in a survey that will facilitate a more fulsome examination of the subject matter. Through the lived experiences of the steering committee members, the group discussions highlighted perspectives and topics that may not have been identified otherwise. Consistent with the known strengths of a PAR approach, the methodology was effective in engaging underrepresented individuals (Dudgeon, et al., 2017; Glassman & Erdem, 2014). The use of technology was also of benefit to this group. It is known that technology can be effectively leveraged to conduct research across multiple sites and is often used to gather information in youth-led PAR (Gibbs et al., 2020). Conducting steering committee meetings via videoconference allowed individuals to connect in real-time while physically located in multiple regions across the province. In addition to reducing the time and effort required of committee members for participation, this method of communication proved to be vital as many meetings occurred when in-person gatherings were restricted in the province of Ontario due to COVID-19 considerations. Additionally, providing online access to meeting minutes, agendas, and meeting materials allowed steering committee members to contribute or make changes to these documents at their convenience. This flexibility allowed for active involvement and participation of all steering committee members and was inclusive of varied availability and communication preferences across committee members. In addition, providing access to the survey questions through Qualtrics not only allowed steering committee members to experience the survey as survey participants would but also allowed the steering committee members to complete this review at their convenience. This flexibility in the survey review process allowed steering committee members to develop thorough, thoughtful, and intentional feedback.

However, the PAR process was not without challenges. Although the group was able to reach a consensus in most decisions, there were some topic areas and decisions where the group did not initially agree. However, the additional time required for these discussions did result in minor delays in the research process, consistent with known challenges in PAR focusing on post-secondary students with ASD (MacLeod, 2010). Notably, in determining if the topics of spaces and extracurriculars, supports and services, and academic accommodations should be explored with a quantitative or qualitative emphasis, the group was divided. Although the group may have resolved this matter through continued discussion, a creative solution to include matched subsets of qualitative and quantitative questions in the pilot survey was proposed. A comparison of these subsets was explored in Study 3.

Overall, the phases completed in this study adapted from the process described by McCalman and colleagues (2017) were effective in supporting the development of a survey using a PAR approach. Specifically, beginning by defining the logic and exploring the evidence helped to ensure that all participants had similar knowledge of the current research and project aims. This review of the literature provided a foundation for discussions of survey development during the next phase, collaboration as a steering committee. Steering committee members identified several areas relevant to their lived experiences with post-secondary students and ASD. The depth of breadth of these topic areas contributed to the development of a more thorough survey. Additionally, these discussions likely contributed to the collegial and collaborative atmosphere. Finally, the review of the survey with an emphasis on feasibility and relevance allowed the steering committee to refine the concepts and topics identified through the previous stages of survey development.

**Important topic areas.** The steering committee identified a large number of topic areas as important for inclusion in the survey as presented in the mind map. Some of these topic areas were broad, while others were highly specific. Some topic areas were highly interrelated, while others were more separate. The mind map assisted in providing a visual representation of the depth and breadth of each larger subject identified as important for inclusion. The visual representation was also helping in guiding discussions as a steering committee regarding relative emphasis and priority for topic areas with different highlighter colours. The large number of topic areas presented on the page made it clear that revision and reduction were important to develop an effective and high-quality survey.

**Technological features and approaches.** Steering committee members also shared their perspectives on the technological features and approaches that they believed would enhance the survey. For example, the steering committee agreed that using survey logic to incorporate the participant's preferred term related to ASD would support a positive user experience and increase the probability of survey completion. The steering committee also identified additional suggestions for adjustment in areas that they believed would enhance the user experience and minimize any potential discomfort. For example, the steering committee opted to explore participant identity using open-ended questions versus a defined list that was potentially restrictive or could omit an important option for a participant. Specific words and phrases were also identified as preferable. In addition to enhancing the user experience and minimizing discomfort, the steering committee selected these words and phrases with the intention of increasing the clarity of the survey questions. Due to the size of the proposed survey, it was understandable that the steering committee focused on reducing response effort and the number of questions presented wherever possible, such as by instructing participants to skip rows in

matrix-style questions that did not apply to their experiences or by utilizing survey logic to redirect participants to skip questions that were irrelevant to their experiences.

**Final content and format.** The steering committee generally reached consensus on the final content and format of the survey measure. The steering committee developed a mixed methods survey with a relatively equal emphasis on qualitative and quantitative methods grounded in pragmatism with consideration of the topic area to be explored. However, as the steering committee did not reach consensus on the best method to explore spaces and extracurriculars, supports and services, and academic accommodations, the final survey measure included both a quantitative and qualitative subset of questions to explore these topics.

The topic areas identified by the steering committee and included in the survey measure developed for pilot testing generally aligned with the existing research conducted in countries outside of Canada. For example, the exploration supports and services with an emphasis on academic accommodations was a common area of focus in the research focusing on post-secondary students on the autism spectrum (e.g., Anderson et al., 2018; Barnhill, 2016). Additionally, other studies have focused primarily on supports and services accessed by students (e.g., LeGary, 2017; Cai & Richdale). Previous studies have also reported detailed demographic information, such as mental or physical health concerns, and the education status of participants (e.g., Anderson et al., 2018; Cai & Richdale, 2016; Gurbuz et al., 2019). Although the inclusion and emphasis on student strengths and skills was somewhat unique, the areas of need, representative of areas of difficulty or skill deficit were often an area of focus in the research literature (e.g., Knott and Taylor, 2014; White, Elias, et al., 2016). Some recent research has included a more balanced and comprehensive approach by reporting on relevant strengths and limitations, similar to the survey developed by this steering committee (e.g., Anderson et al.,

2018; Gurbuz et al., 2019). The current body of research also included exploration of experiences with spaces and extracurriculars on campus (e.g., Madriaga, 2010). However, few studies have focused on experiences related to employment and experiential learning; a study focusing on outcomes related to a mentorship program conducted by Koegel, Ashbaugh, Koegel, Detar, and Register (2013) included questions about employment but did not focus on this outcome. It was expected that the topic areas identified by the steering committee would be similar to those explored in the existing literature. Although the experiences of Canadian Autistic post-secondary students may differ from that in other countries, the opportunities and experiences available on campus are similar. Additionally, this measure has the potential to contribute meaningfully to the broader literature by exploring all of these important topic areas within one survey measure to facilitate increased opportunities for analysis and comparison.

**Strengths.** The primary strength of the present study was the inclusion of individuals with lived experiences in all aspects of the action inquiry process, consistent with the definition of PAR provided by Chevalier and Buckles (2019). This study provides a model for future research using a PAR approach. This study also contributed to the limited body of research exploring applications of PAR in research focusing on the experiences of Autistic post-secondary students.

**Limitations.** One limitation of this study was the size of the steering committee. Although the members contributed substantial time and expertise to the project, it is possible additional areas of importance would have been identified with a larger group of contributors. This limitation could be addressed through conducting pilot testing with a large and diverse group of individuals with recent experiences attending post-secondary studies in Canada. Additionally, this study would have been enhanced by gathering information regarding the



experiences and perspectives of the steering committee members in relation to the PAR process. Due to limitations related to time and availability, this information was not collected but will be an area of focus as the larger research project continues.

**Future directions.** Future research should continue to examine applications of PAR with post-secondary students with ASD. This research methodology would serve to ensure the relevance and credibility of results as well as continue to build on this limited topic in research. Additionally, although the areas of interest included in the survey aligned with the existing research, this study did not explore how the experiences of Canadian Autistic post-secondary students differ from that of students in other countries. These differences and similarities will be explored further in Study 2.

**Conclusion.** Overall, this study was successful in using a PAR approach to develop a draft survey examining the strengths, experiences, and needs of Canadian Autistic post-secondary students in preparation for a survey pilot. The success of this study demonstrated the importance of collaboration with individuals with lived experience in enhancing research and provided additional support for survey development using a similar PAR approach.

### Chapter 3: Study 2

This study explored preliminary findings regarding the strengths, experiences, and needs of Canadian post-secondary students with ASD as reported in a survey pilot. Preliminary findings regarding strengths and challenges, adjustment, service use, and recommendations for the post-secondary setting are discussed.

#### Introduction

It is imperative that research exploring the needs and experiences of college and university students on the autism spectrum seeks the perspectives of Autistic students who have attended or are attending post-secondary studies. The credibility and relevance of findings reported from such research should amplify these perspectives.

**Post-secondary students on the autism spectrum.** Although research exploring the perspectives of Autistic post-secondary students is limited, some studies have examined strengths, experiences, and needs reported exclusively by students (e.g., Anderson et al., 2018; Cullen, 2015; Gelbar, Shefcyk, & Reichow, 2015; Jackson, Hart, Brown, & Volkmar, 2018; Sarrett, 2018; Van Hees et al., 2015; Vincent et al., 2017).

**Strengths.** Research examining the self-reported strengths of post-secondary students with ASD is particularly limited. Although this area was not the sole focus of any study encountered, several studies included discussion of individual strengths identified by Autistic post-secondary students (e.g., Anderson et al., 2018, Gelbar et al., 2015; Van Hees et al., 2015). Academic skills have been self-identified as an area of particular strength by post-secondary students on the autism spectrum (Anderson et al., 2018, Gelbar et al., 2015; Van Hees et al., 2015). Specifically, in analyzing the results of a web-based questionnaire administered to 48 Australian Autistic post-secondary students, Anderson and colleagues (2018) found that

participants commonly identified attention to detail, proficiency with technology, creative thinking, memory, and consistency as strengths. Studies in this area have also reported some non-academic strengths. Through conducting semi-structured interviews with 23 students with ASD studying in Belgium, Van Hees et al. (2015) found self-reported strengths related to interpersonal communication, specifically sincerity, objectivity, and willingness to listen.

**Experiences.** Studies reporting on supports, services, and spaces accessed by students on the autism spectrum often included a focus on academic accommodations (e.g., Anderson et al., 2018; Gelbar et al., 2015; Sarrett, 2018). In exploring the on-campus experiences reported by 35 current college students in the US through an online survey, Gelbar and colleagues (2015) found that the majority of the sample (97%) preferred to spend their time on campus in quiet spaces. However, more than half of this group (56%) also reported that they are lonely on campus. In exploring the non-academic supports accessed by Autistic students, Anderson and colleagues (2018) found that the majority of students in the survey sample had participated in orientation programming (63%), second in frequency only to consultation with disability supports (83%). This study found that 57% of participants attending orientation programming identified this support as somewhat or very helpful.

Some studies have also explored the experiences of Autistic post-secondary students more broadly (e.g., Jackson et al., 2018; Vincent et al., 2017). A study conducted by Jackson and colleagues (2018) explored the academic, social, and mental well-being experiences of 56 post-secondary students on the autism spectrum studying in the US, Canada, and UK. The authors found that 75% of participants had experienced some form of lifetime suicidal behavior, with 54% of that group experiencing suicidal ideation in the last year. The authors also reported that participants experienced extremely severe symptom levels of depression and severe levels of

stress, on average, as assessed through the 21-Item Depression Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995). Through a PAR approach, Vincent and colleagues (2017) explored the lived experiences of seven Autistic student researchers in the UK. This study identified a sense of difference, social interactions, responding to change and independence, and fear versus reality as themes that emerged through an analysis of critical autobiographies.

**Needs.** In exploring the post-secondary experiences, strengths, and challenges reported by Autistic post-secondary students, several specific areas of need have been identified (e.g., Cullen, 2015; Gelbar et al., 2015; Jackson et al., 2018; Van Hees et al., 2015; Vincent et al., 2017). Specifically, students on the autism spectrum identified social skills, such as making connections, executive functioning skills, including time management, daily living skills, such as navigating transportation, and academic skills, like navigating group work, as areas where additional support and exploration were required. Cullen (2015) used naturalistic inquiry, including an online questionnaire, individual interviews, and focus groups, to explore the areas of need reported by 24 Autistic post-secondary students in the US. This study identified social needs, academic needs related to group work, and daily living needs as themes that emerged through analysis. Areas of difficulty identified included meeting more or more compatible people, finding places to meet people, managing the social elements of group work, and developing and maintaining a schedule addressing academic and daily living needs.

**Methodology.** To support the development of effective and high-quality research, all decisions related to research design should be made with consideration of the relevant literature.

**Recruitment.** There are several notable limitations related to participant characteristics in this area of research. One common limitation is the overrepresentation of individuals connected with disability support offices (e.g., Anderson et al., 2018; Cullen, 2015). Although all

participants in the study conducted by Anderson et al. (2018) were recruited through the disability services office, 25 percent of participants in the study reported delaying disclosure and may not have been contacted if recruitment were conducted earlier. Gelbar and colleagues (2015) reported distributing recruitment materials to self-advocacy groups, parent organizations, and disability services offices to access potential participants. The authors found that 69% of participants disclosed disability within the first semester and 80% disclosed to disability service coordinators in total.

Another limitation identified in the literature is the lack of Autistic individuals who were previously enrolled in but did not complete post-secondary studies (e.g., Gelbar et al., 2015). Research focusing on Canadian Autistic post-secondary students is very limited; one study conducted by Ames and colleagues (2016) focused on the evaluation of a mentorship program for 23 university students on the autism spectrum, while one study conducted by McMorris and colleagues (2019) focused on experiences related to mental health service access for 45 Canadian undergraduate students. Surveys of post-secondary students with ASD outside of the US and UK were identified as a direction for future research (e.g., Anderson et al., 2017).

**Measures.** Including standardized measures in quantitative research serves to reduce systematic bias, thereby enhancing validity (Yardley & Bishop, 2017). Incorporating a norm-referenced measure also facilitates comparison with a larger population and mitigates issues related to sample size. Additionally, using standardized measures increases validity as administration includes replicable and defined scoring procedures.

*Student adaptation to college questionnaire.* The Student Adaptation to College Questionnaire (SACQ; Baker & Siryk, 1989) is a standardized measure which references an established norm. This norm-referenced 67-item questionnaire was developed to assess

adjustment to the post-secondary environment as reported by the student as compared to post-secondary students at large. In addition to a total adjustment score, this self-report questionnaire generates four subscales to assess academic adjustment, social adjustment, personal-emotional adjustment, and attachment. The academic adjustment scale assesses a student's capacity to cope with academic or educational demands, the social adjustment scale measures the student's ability to cope with social or societal demands, the personal-emotional adjustment scale assesses the student's physical and mental well-being, and the attachment scale quantifies the student's satisfaction with the college or university attended. Research focusing on the Student Adaptation to College Questionnaire (SACQ; Baker & Siryk, 1989) has established the existence of a strong relationship between adjustment to college and measures of student success, namely grade-point average (GPA) and retention (Credé & Niehorster, 2012).

The SACQ has been used extensively in research to assess student adjustment to post-secondary education (e.g., Krajniak, Pievsky, Eisen, & McGrath, 2018; McAndrew et al., 2019; Ramler, Tennison, Lynch & Murphy, 2015). This measure has also been used in research with individuals on the autism spectrum and individuals exhibiting autistic traits (e.g., Trevisan & Birmingham, 2016; White, Richey, et al., 2016; Wise, 2015). In a dissertation evaluating a post-secondary support program for individuals on the autism spectrum in the US, Wise (2015) reported that the average adjustment scores for 15 students at the fourth week of the academic year were within the average range for all subscales as well as the total scale, with the mean *t*-scores for academic adjustment and personal emotional adjustment slightly above the norm-referenced mean, and the mean *t*-scores for social adjustment, attachment, and the full scale slightly below the norm-referenced mean. White, Richey, and colleagues (2016) used the SACQ to assess adjustment of college students in the US at baseline and post-intervention in a comparison

of two intervention programs but reported no meaningful changes in adjustment. Additionally, although the study conducted by Trevisan and Birmingham (2016) focused on individuals who met criteria for ASD characteristics as measured by the Broad Autism Phenotype Questionnaire (BAPQ; Hurley et al., 2007) and zero participants reported a diagnosis of ASD, this study still contributes meaningfully to this limited area. In examining the adjustment of 153 Canadian undergraduate students, the authors found that individuals who met BAPQ criteria scored lower, on average, on the academic, social, and personal-emotional adjustment subscales, with significant differences reported for the academic adjustment and social adjustment subscales. The attachment subscale and full scale scores were not reported in this study.

The reliability and validity of the SACQ has been explored extensively in research. A recent meta-analysis conducted by Credé and Niehorster (2012) reported good estimates of internal consistency (mean alpha  $>0.82$ ) for each of the SACQ sub-scales in addition to the full scale, with the mean square root of reliabilities for the sub-scales and full scale ranging from 0.91 to 0.96. This meta-analysis included 237 independent samples for a total sample size of 44,668 students attending undergraduate studies primarily in the US and Canada. The authors reported relationships between adjustment to college overall and important measures of post-secondary success, specifically student GPA (Std. beta = 0.23) and retention (Std. beta = 0.20), both representative of moderate correlations. It was noted that the size of the relationship between adjustment and both GPA and retention compared favorably with some of the strongest known predictors in existing research, such as SAT scores and study habits. In exploring the predictive validity of the SACQ, the authors of this meta-analysis reported that academic adjustment, in particular, was a moderate predictor of GPA (Std. beta = 0.33), while attachment was identified as a moderate predictor of student retention (Std. beta = 0.28). High test-retest

reliability and adequate construct and predictive validity were also reported by Baker and Siryk (1989). The SACQ was used in this study to provide contextual reference regarding the adjustment of the participants relative to established norms for post-secondary students at large. Wording on a few questions (e.g., the opposite sex) was changed with permission of the publisher in order to promote inclusivity.

### **Purpose**

The purpose of this study was to report on preliminary findings of a survey examining the strengths, experiences, and needs of Canadian Autistic post-secondary students as reported by these students.

### **Research Questions**

This study examined the following research questions:

1. What was the relative post-secondary adjustment of this pilot group compared to a norm-referenced sample?
2. What were the strengths and needs reported by this pilot group of post-secondary students with ASD?
3. What supports and services were accessed by this pilot group of post-secondary students with ASD and to what degree do they report their needs being met?
4. What recommendations for improvements to the post-secondary environments were made by this pilot group?

### **Method**

This study used a mixed methods research design, specifically a convergent parallel design (Creswell & Plano Clark, 2011). Overall, the research design was most consistent with the parallel-databases variant of the convergent parallel design as qualitative and quantitative



data were collected independently within the same phase of research, with each strand analyzed separately and integrated during interpretation.

**Participants.** The survey was completed by 12 individuals who self-identified as Autistic and had completed at least one semester of college or university in Ontario. Due to the recruitment method through participant’s personal or professional relationships with the steering committee and close colleagues, confirmatory diagnostic information was not requested. All participants had been enrolled in studies within the last five years with the exception of one participant. See Table 3-1 for a summary of participant demographic characteristics and Table 3-2 for a summary of the most recent post-secondary experiences reported by participants.

Table 3-1

*Participant Demographic Characteristics*

Demographic Characteristics	Number of Participants (%)
Age	
21	1 (8.33%)
23	2 (16.67%)
24	2 (16.67%)
25	1 (8.33%)
26	1 (8.33%)
27	1 (8.33%)
28	2 (16.67%)
31	2 (16.67%)
Gender Identity	
Male	6 (50.00%)
Female	2 (16.67%)
Non-Binary	2 (16.67%)
Trans Masculine	1 (8.33%)
Unsure	1 (8.33%)
Sexual Orientation	
Aromantic asexual	1 (8.33%)
Asexual	2 (16.67%)
Bisexual	4 (33.33%)
Demisexual	1 (8.33%)
Heterosexual	1 (8.33%)
Queer	1 (8.33%)
Physical Health Concerns	

Allergies	3 (25.00%)
Asthma	4 (33.33%)
Cellulitis	1 (8.33%)
Graves' disease	1 (8.33%)
Irritable bowel syndrome	1 (8.33%)
Mobility or dexterity disability	1 (8.33%)
None	4 (33.33%)
<b>Mental Health Concerns</b>	
Anxiety	10 (83.33%)
Attention deficit hyperactivity disorder/attention deficit disorder	6 (50.00%)
Depression	4 (33.33%)
None	1 (8.33%)
<b>Learning Difficulties</b>	
Math	2 (16.67%)
Non-verbal	4 (33.33%)
Non-verbal cues	1 (8.33%)
Reading	3 (25.00%)
Reading comprehension	1 (8.33%)
Writing	3 (25.00%)
None	3 (25.00%)

In describing their identity in relation to culture and ethnicity, participants self-identified as Canadian, Chinese, Black, Indian, African, Asian, Franco Ontarien, Vietnamese, White, and Aspergirl, with three participants identifying with more than one group. In describing their creed, faith, or religious identities, participants self-identified as Atheist, Buddhist, Christian, Secular, and Roman Catholic. The majority of participants (58.33%,  $n = 7$ ) did not identify with any creed, faith, or religion. In disclosing physical health concerns two participants (16.67%) reported experiencing more than one physical health concern, six participants (50.00%) reported experiencing one physical health concern, and four participants (33.33%) reported no physical health concerns. In disclosing mental health concerns, seven participants (58.33%) reported experiencing more than one mental health concern, four participants (33.33%) reported experiencing one mental health concern, and one participant (8.33%) reported no mental health

concerns. A total of nine participants (75.00%) reported experiencing learning difficulties, with four participants (33.33%) reporting difficulties in more than one area.

Table 3-2

*Participant Post-Secondary Experiences*

Student Status	School	
	College	University
Currently Enrolled	1(8.33%)	5 (41.57%)
Graduated	3 (25.00%)	2 (16.67%)
Not Enrolled, Planning to Return	-	1 (8.33%)

**Recruitment.** Recruitment for this study was not random. The approach used was most consistent with critical case non-random sampling (Onwuegbuzie & Collins, 2007). Members of the steering committee contacted potentially eligible and interested individuals in their personal and professional networks by email to share a letter of invitation (Appendix A). Recruitment procedures were revised to include participants who had attended post-secondary studies within the last five years (increased from two) and contact of potential participants by clinicians and graduate students known to the steering committee. These individuals contacted potential participants using a revised email template. In total, 31 potential participants were contacted.

**Compensation.** Participants received compensation for participation in the form of an electronic transfer of funds or cheque provided by mail. Participants received 25 dollars for each survey part that they completed in part or in full, to a maximum of 100 dollars. Participants provided information about their preferred method of payment and parts completed by email.

**Consent.** Participants were provided with information relevant to the study as well as the opportunity to ask any questions and have questions answered to their satisfaction. Participants were encouraged to consult with a parent, friend, or teacher before agreeing to participate. Participants were informed that consent could be withdrawn at any time for any and all aspects

of involvement. Participants were also provided with the opportunity to provide consent for their data to be retained for re-analysis as well as to be contacted regarding future research.

**Procedure.** The survey developed by the steering committee was separated into three parts: Part A, Part B, and Part C. A fourth section, Part D, allowed participants to provide feedback on the survey. The administration of Part D was explored in Study 3. All survey parts were provided as a web-based survey using Qualtrics XM Software (Qualtrics, 2020). The survey was self-paced and allowed participants to complete all parts of the survey across as much time and as many sittings as required. After expressing interest in participating in the research project, participants were provided with a link to Part A by email. For Parts A through C, after completing each subsequent part of the survey, participants were provided with the option to move on to the next part of the survey or to request a link to the next part by email. Links were provided within two business days. If participants did not respond within five business days, the research team followed up to offer support and alternative options, such as providing responses over the phone. If participants did not complete a survey section within seven days, the session was automatically terminated. When required, the research team contacted participants to inform them and offer alternatives, such as starting a new survey session to answer any remaining questions.

**Survey.** Each part of the survey asked participants to identify one term related to the autism spectrum that they most identified with, as well as their most recent post-secondary setting (i.e., college or university). These phrases were incorporated in future questions using the Piped Text feature in Qualtrics XM Software (Qualtrics, 2020) to provide an individualized survey experience consistent with individual preferences and experiences. Additionally, survey logic tools were used to minimize the number of irrelevant questions presented to participants.

For example, if a participant reported that their program did not offer experiential learning opportunities, participants were not asked additional questions about experiential learning and were directed to the next survey section.

Part A of the survey included 190 qualitative and quantitative questions. This section included the consent, demographic, and participant demographic information questions, in addition to questions exploring student experiences related to: education status; strengths, skills, and experiences; experiential learning; employment; and previous education.

Parts B and C of the survey focused on participant's experiences with spaces and extracurriculars, supports and services, and academic accommodations. Part B included 33 qualitative questions, with four quantitative questions to guide survey logic and prevent participants from being asked to respond to questions that did not match their experiences. Part C consisted of 22 quantitative questions and three qualitative questions focused on participant's overall experience and any subjects considered important but not included in the survey.

*Measures.* Part A also included questions from the SACQ (Baker & Siryk, 1989), a 67-item self-report inventory, which was embedded within the survey under license from WPS Publishing with minor adjustments. Specifically, the word university replaced the word college as needed, consistent with participant's experiences. Additionally, the phrase "the opposite sex" was replaced by "people of other genders" in one question to be more sensitive to the range of genders. This measure is generally completed in 15 to 20 minutes. Each item is presented as a statement where participants may respond using a nine-point Likert-type scale anchored with the statements *Applies Very Closely to Me* and *Doesn't Apply to Me at All*. This standardized measure was used to support comparison to the norming sample and other published samples.

**Data collection.** Responses to survey questions were recorded in Qualtrics XM software. To prepare response data for analysis, participant responses from Part A and Part C were exported to a file format compatible with IBM SPSS Statistics (Windows, Version 26.0; IBM Corp., 2019) and participant responses from Part A and Part B were exported to a file format compatible with Microsoft Excel (Microsoft Office 365 MSO, Version 2008; Microsoft Corporation, 2020).

**Analysis.** Participant responses were analyzed using qualitative and quantitative methods. Although this expansive survey produced a large dataset, analysis in this study focused on participant strengths, experiences, and needs.

**Qualitative.** Several qualitative survey items were analyzed using thematic analysis (Braun & Clarke, 2006) to identify main overarching themes and sub-themes. The qualitative analysis process followed the phases of thematic analysis described by Braun and Clarke (2006), specifically: (a) familiarizing yourself with your data; (b) generating initial codes; (c) searching for themes; (d) reviewing themes; (e) defining and naming themes; and (f) producing the report. To increase familiarity with the data, participant responses were reviewed, and potentially relevant aspects were highlighted in a document created using Microsoft Word (Microsoft Office 365 MSO, Version 2008; Microsoft Corporation, 2020). Next, initial codes were generated and listed in point form. Following a period of review, these codes were grouped and organized in a table by candidate themes. These candidate themes were reviewed and revised, resulting in the final defining and naming of these themes, before the report was produced. To facilitate verification of the findings and evaluate the trustworthiness of the thematic analysis process, detailed notes relevant to the thematic analysis process were reviewed by a research assistant who was not a member of the steering committee or otherwise involved in research; agreement

was reached for all themes and sub-categories through peer debriefing (Nowell, Norris, White, & Moules, 2017).

Archetypal excerpts of themes were selected from participant responses. Consistent with the recommendations of the American Psychological Association (2019) regarding gender and bias-free language, as participants had not reported their pronouns, the singular “they,” or “their” was used in association with participant response excerpts. This also served to protect participant privacy and confidentiality within the small sample of pilot participants. Word clouds of 25 prominent words were generated from participant responses to specific survey items utilized for thematic analysis using Qualtrics XM Software (Qualtrics, 2020). Words that did not contribute meaningfully to analyses, such as *can't* or *school*, were removed. A list of survey items which were the focus of qualitative analysis can be found in Appendix B.

Qualitative analyses were used to validate the quantitative results regarding service use, consistent with the data-validation variant of a convergent parallel mixed methods research design. Specifically, supports and services reported in response to specific qualitative survey items were converted to a quantitative count and presented in a table to facilitate comparison with the quantitative survey items exploring the use of supports and services.

*Quantitative.* Participant demographics, survey completion, adjustment, and service use were analyzed using quantitative methods. Descriptive analyses were used to analyze participant demographic data. Survey completion was assessed using a simple count of the number of individual participants completing each survey section.

Participant service use, needs, and satisfaction were analyzed using Qualtrics XM Software (Qualtrics, 2020), specifically the Crosstabs tool in the data and analysis section was

used to produce contingency tables exploring the relationship between the frequency of service use, the degree to which needs were met, and participant satisfaction.

Adjustment to the post-secondary setting was assessed using the 67 SACQ items. Total scores were generated for the full scale and four subscales as per procedures outlined in the SACQ manual (Baker & Siryk, 1999). These scores were converted to norm-referenced percentile rank equivalent scores as per the SACQ manual. In preparation for scoring procedures, participant responses for each item were entered in IBM SPSS Statistics (Windows, Version 26.0; IBM Corp., 2019). Data cleaning procedures were conducted to identify errors and missing responses. Additionally, as the scale had been presented in reverse in the survey, the transform function was used to recode all variables. As per the SACQ Manual (Baker & Siryk, 1999), specific items were reverse-coded, with data recoded into the same variable using the transform function. Additionally, one missing score for one participant was replaced with the average score for the associated subscale, as per the procedure outlined in the SACQ manual.

Individual participant demographics, including age, sex, and post-secondary status were used to determine participant adjustment scores for this norm-referenced measure. Options for post-secondary status included participant's current or most recent academic year and semester. The responses provided by transgender participants were assessed using the sex that aligned with the participant's gender identity. For participants who identified as non-binary, scores were assessed using the biological sex that best aligned with points of inference within their survey responses, such as the first name reported by participants.

*Integration.* Consistent with the parallel-databases variant of the convergent parallel design described by Creswell and Plano Clark (2011), qualitative and quantitative data were



analyzed and presented independently in the results, then integrated for the interpretation of the results outlined in the discussion section of this study.

## Results

Of the 12 participants, 12 completed some or all of Part A of the survey, 11 completed Part B, and 10 completed Part C. Since the survey parts were provided in sequence, the survey was completed in full by 10 participants.

**Post-secondary adjustment.** The post-secondary adjustment of pilot participants was assessed using the SACQ (Baker & Siryk, 1989), with individual and group scores reported with reference to the norm-referenced mean, a percentile rank equivalent score of 50 ( $SD = 35$ ). Overall, the pilot sample reported average mean scores for the academic adjustment and personal-emotional adjustment subscales, with the range of participant scores within the average and below average range. The pilot sample reported below average mean scores for the full scale and attachment subscale, with the range of participant scores within the average and below average range, while both the mean score and range of scores for the social adjustment subscale were below average as compared to the post-secondary student population at large. Individual participant scores as compared to the mean standard score are presented in Figure 3-1.

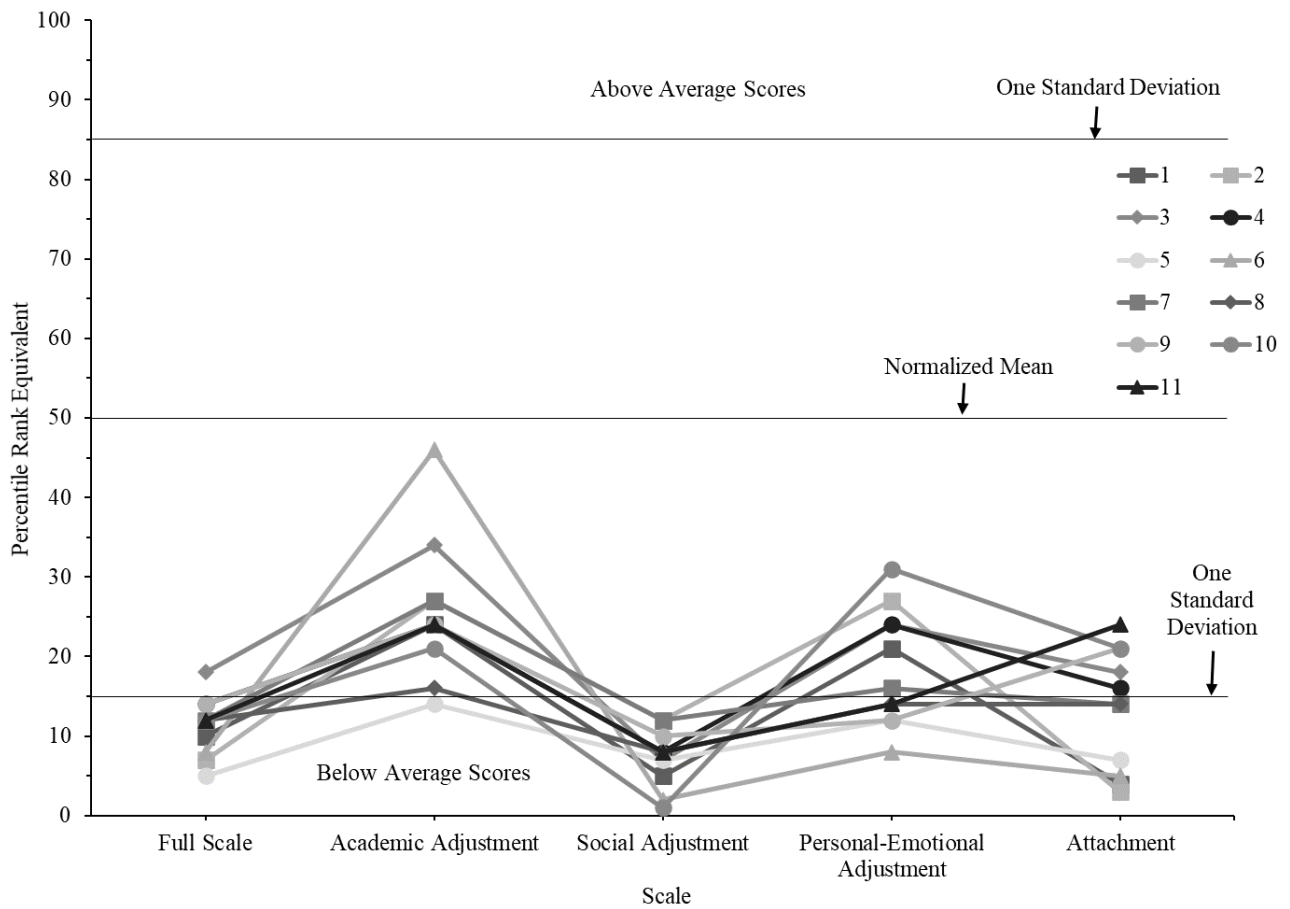


Figure 3-1. Individual participant scores for SACQ with normalized mean and standard deviation of normalized mean identified.

**Summary.** Notably, none of the participants in this group scored above the normalized mean for any subscale or the full scale. The patterns of post-secondary adjustment which emerged through analysis of the SACQ scores were relatively consistent with the qualitative and quantitative results presented in the following section where strengths identified were often academic in nature, and areas of challenge were often social in nature.

**Strengths and needs.** Through thematic analysis of participant responses, several relevant themes emerged which related to personal and academic strengths, as well as personal and academic limitations, or areas of need.

**Strengths.** Participants reported several areas of strength in response to the relevant survey items. Through the analysis of participant responses, seven sub-categories across two themes emerged. The relationships between the themes were represented in the thematic map presented in Figure 3-2. A word cloud generated from participant responses is presented in Figure 3-3.

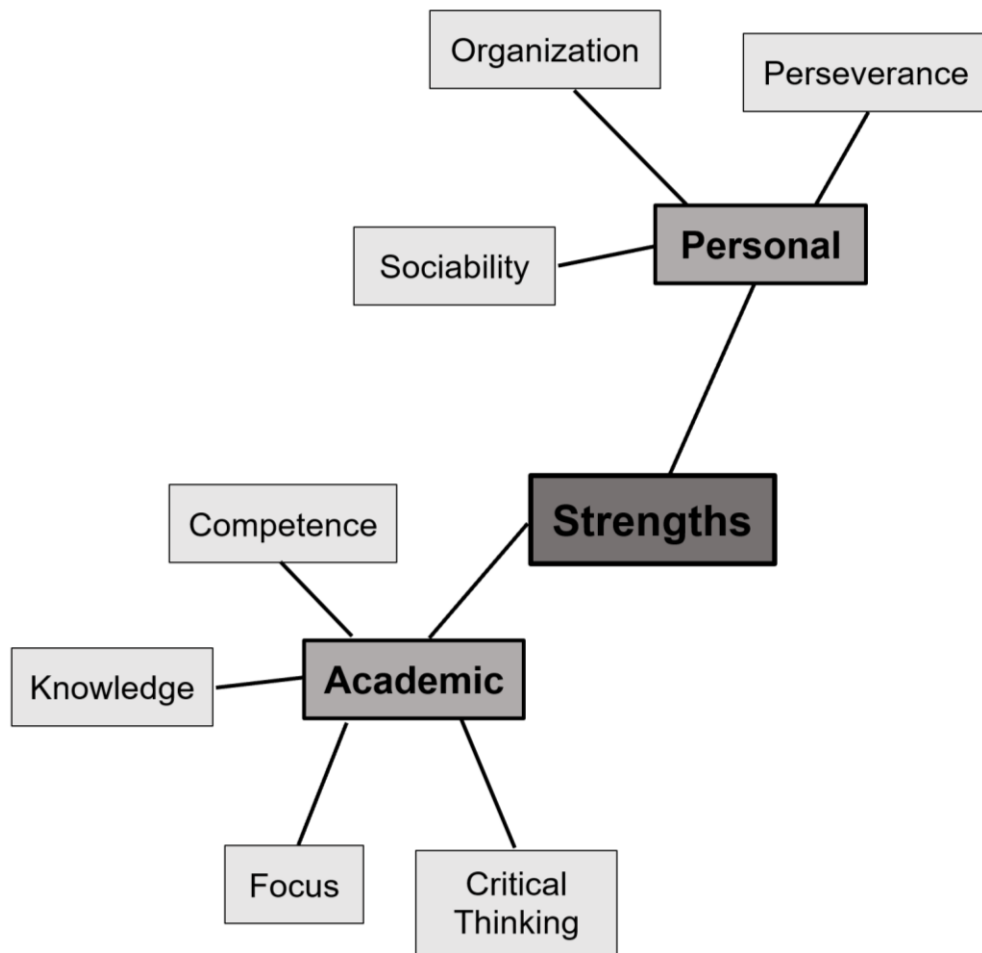


Figure 3-2. Thematic map of analysis completed for participant responses related to personal and academic strengths.



Figure 3-3. Word cloud of participant responses to “Please describe your personal strengths and academic strengths that have helped you on your path to success at school.”

*Academic strengths.* The theme of academic strengths emerged through the analysis of participant responses.

Participants expressed confidence in their ability to succeed academically. This sub-category, summarized as *competence*, emerged in relation to responses identifying intelligence and the ability to “absorb” information well in lectures. One participant reported feeling proud that they had graduated “with honors” and excelled in the subjects such as “computers and math.”

The sub-category of *critical thinking* emerged as critical and analytical thinking were identified by participants as areas of strength relevant to their post-secondary experience. One participant described an area of strength as being “active and insightful during class discussions.”

The sub-category of *focus* emerged through analysis of feedback related to the singular focus on course work, particularly when focusing on a topic that is of interest to the participant. One participant identified an academic strength as the “ability to enter “deep work”: a state of

continuous uninterrupted work,” a concept which was credited to Cal Newport (2016). While another described an area of strength as “having the ability to focus on tasks until its done.”

The sub-category of *knowledge* emerged through responses related to knowledge specific to the program of study and more broadly. One participant identified a “broad base of general knowledge” and “strong memory” as areas of strength which were helpful on the path to academic success.

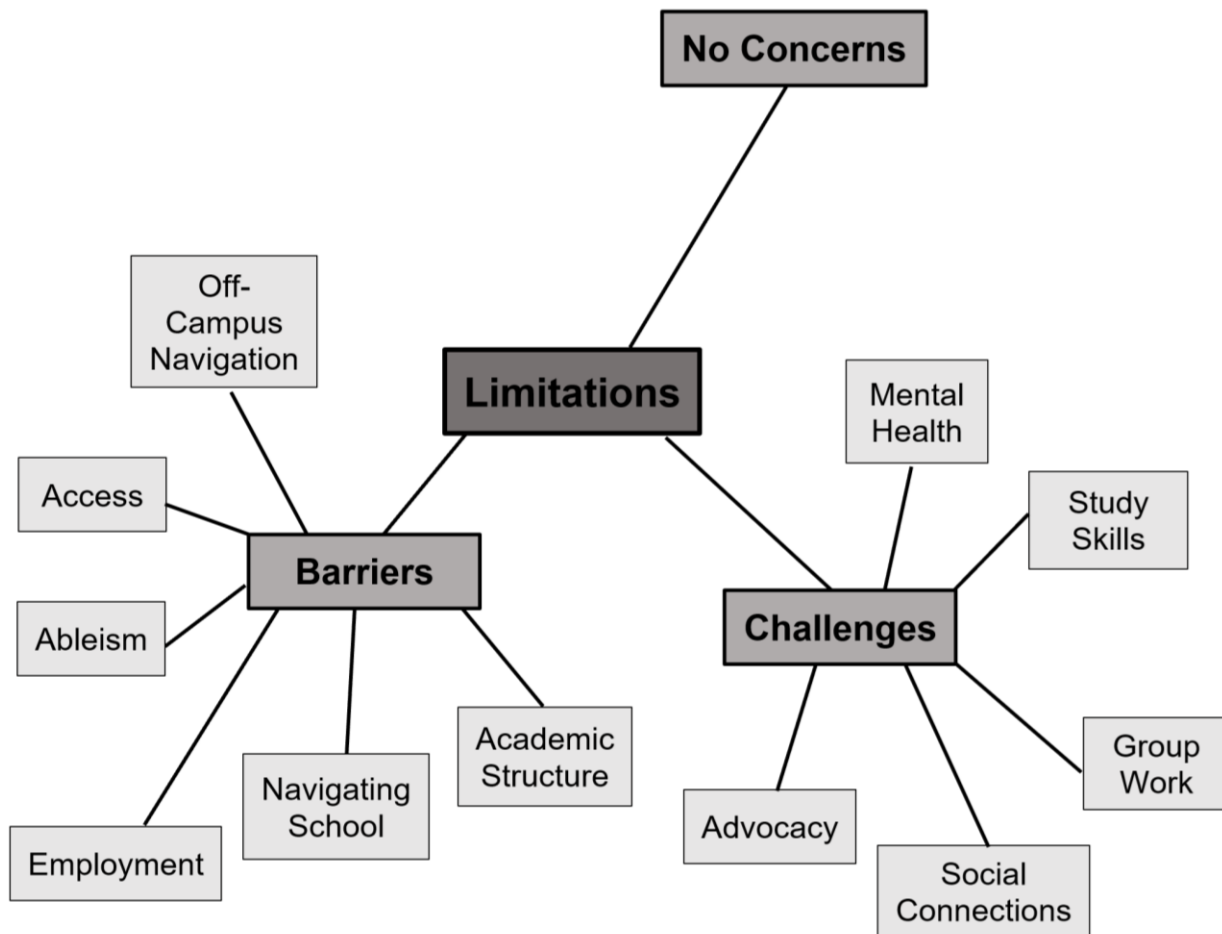
*Personal strengths.* The theme of personal strengths related to skills and strengths that were unrelated to academic achievement.

The sub-category of *perseverance* emerged in relation to responses where participants described themselves as “resourceful,” “independent” and “able to advocate for myself.” One participant reported that strengths in this area were important for “self preservation and self-perseverance that kept [them] afloat” Participants identified that this attribute supported their ability to complete academic work and meet personal and academic needs.

Another sub-category which emerged within this theme was *sociability*. Some participants reported that they possessed personal strengths related to interpersonal relationships, such as being “funny,” “nice,” or “able to communicate with people.” Participants identified that these strengths helped them to connect with their peers. This sub-category was exemplified by one participant’s response identifying that “I have been more outgoing and able to befriend my class mates more easily.”

The sub-category of *organization* also emerged through thematic analysis. Participants described areas of strengths which helped them on the path to success at school as being “detail-oriented” and “organized.” One specific example related to this attribute was that one participant consistently submitted assignments and projects on time.

**Limitations.** Three themes emerged through analysis of participant responses in relation to limitations: challenges, barriers, and no concerns. The relationships between these themes are represented in the thematic map presented in Figure 3-4.



*Figure 3-4.* Thematic map of analysis completed for participant responses related to personal and academic limitations.

**Challenges.** Participants reported several personal and academic challenges or areas of limitation. A word cloud generated from participant responses is presented in Figure 3-5.

Through the analysis of participant responses, five sub-categories emerged in relation to the larger theme.

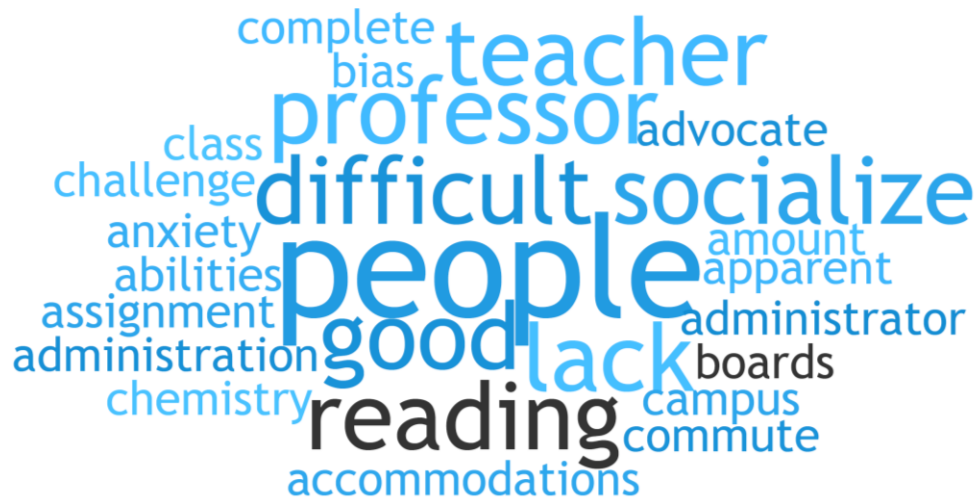


Figure 3-5. Word cloud of participant responses to “Please describe any personal limitations and academic limitations that may have impacted your success at school.”

The first sub-category that emerged related to *social connections*. Participants identified that socializing was difficult and draining. One participant reported that “I was drained/couldn't focus well for the first few weeks” after participating in orientation. Participants also reported an unmet desire for social connection, despite trying to establish clubs for students with disabilities or seeking “fellow Autistics/Aspies” on campus.

Another area of challenge which emerged related to *study skills*, such as time management and maintaining focus. One participant reported that this area was particularly challenging initially: “I struggled with transitioning from high school studying to university studying outside of lecture time. I didn't know how to figure out how to study like a university student effectively.” Developing effective strategies for writing and reviewing lecture notes were also identified as areas of difficulty. One participant identified “letting my liking for leisure reading and watching run away with me a few times” as impacting success at school.

Through analysis of participant responses, a third sub-category emerged related to *mental health*. Participants reported that they were negatively impacted by mental health concerns and

increased levels of stress. Specifically, symptoms of anxiety, depression, and an “inability to relax” were reported as areas of personal limitation. One participant identified “Anxiety, Depression, Trauma from excessive bullying from high school” as areas that impacted success at school, while another stated, “I was always stressed when at school.”

*Group work* emerged as a distinct sub-category of areas of challenge encountered by participants. This sub-category related to experiences of isolation, forced connection, and impacts on academic success. One participant reported a negative experience being “left out of a group I thought I was a part of very early on in the school year,” while another identified experiences with “[u]ncertain, flaky, or uncooperative group members” and the assignment of group members for projects as challenges that impacted success at school.

A final sub-category emerged which related to uncertainty and discomfort with disclosure of disability and advocating for one’s needs, which was summarized as *advocacy*. This sentiment extended not only to academic accommodations on campus, but negotiating difficult circumstances off-campus as well, such as issues related to housing. This sub-category was exemplified by statements such as “I wish that I’d been taught how to negotiate for myself should this or similar housing situations occur” and “I feel uncomfortable disclosing what I might have challenges with to my school.”

*Barriers.* Participants identified several barriers which may have impacted their success at school. A word cloud generated from participant responses is presented in Figure 3-6. Six distinct sub-categories emerged through analysis of responses related to the larger theme of barriers.





*Figure 3-6.* Word cloud of participant responses to “Please describe any obstacles or barriers within the school environment that may have created challenges that impacted on your success at school.”

The first sub-category that emerged through analysis was *access*, which related to academic accommodations and accessibility services. Some participants reported that the supports available did not meet their needs, while others reported that accommodations were not fully implemented. Additionally, one participant highlighted a financial barrier related to access:

“The fact that adult students with developmental conditions are required to pay out of pocket for new psycho-ed reports to access Accessibility Services is a barrier. By definition, developmental conditions are life-long and don't 'go away' at 18, so there is little reason to require a new report just because someone came of age.”

Participants also identified a need for supports, services, and groups related to accessibility that extended beyond academic accommodations.

Participants identified ableist perspectives of staff, faculty, and peers as barriers to post-secondary success, summarized within the sub-category of *ableism*. Participants reported that staff and faculty did not understand matters related to disability and were “not that empathetic

towards students with disabilities.” One participant described an instructor as “dismissive when I tried telling her about terms like "neurotypical" and also when I tried bringing up a concern I had about a particular activity not being accessible to me.” The same participant reported experiencing hurtful incidents related to peers and instructors which resulted in feeling unsafe and unable to engage in class discussions.

The sub-category of *navigating school* was related to both the physical and virtual campus environment. Participants identified confusing campus navigation, dealing with crowded and busy spaces, and “occasional sensory issues around noise” as barriers. Additionally, one participant identified that “[f]iguring out the new student websites (like Canvas) was also very hard and took some getting used to.”

A sub-category emerged through analysis of responses related to barriers outside of the campus environment, described as *off-campus navigation*. Many participant responses related to this sub-category focused on navigation of the physical environment, with the time required for commuting and navigating public transit identified as areas of difficulty. The limited public transit system and cost of taxi transportation were identified by one participant as barriers to participating in events. Another participant reported that “[t]he biggest struggle, challenge or barrier was that when it came to finding a place to live in or around campus.”

The sub-category of *academic structure* related to feedback where participants reported that structures and requirements related to a specific course or school in general had an impact on their success. Participants reported that course requirements and expectations were unclear or confusing. Additionally, the rigidity of post-secondary structures was identified as problematic. One participant identified “[r]igid, conflicting, or competing exam dates and times,” and

“assignment deadlines,” as well as “rigid course grade cutoffs” and “useless prerequisites” as barriers.

Although not closely related to the post-secondary environment, the sub-category of *employment* emerged through analysis. One participant reported negative experiences in previous employment, including “rude and verbally abusive” coworkers. Another participant identified that supports offered by career services were unhelpful. This participant reported that they needed “help creating and maintaining a daily routine around applying for jobs” and “advice on following up after job fairs, including editable email templates.”

*No concerns.* The final theme which emerged through analysis related to one specific response. However, the divergence of the content of this response required the inclusion of a third theme. Specifically, one participant reported that “there wasn't any obstacles/barriers within the school environment that I can think of that created challenges for me in my academics.”

*Summary.* Overall, the strengths and areas of need reported by participants corresponded closely with the supports and services accessed by this pilot group.

**Supports and services.** Information regarding the frequency of access, efficacy of, and satisfaction with supports and services accessed by this pilot group was solicited through qualitative and quantitative items. Participants reported accessing various supports and services in response to qualitative items. The information provided in responses to qualitative items was somewhat limited in terms of reporting on the degree to which their needs were met and satisfaction in relation to specific services accessed. Participants generally listed the supports and services that they had accessed during their time at school. Most supports and services identified as accessed by participants were included in the quantitative questions in Part C. However, some

additional novel supports and services were identified, specifically life coaching and finance services.

Participants reported the frequency of access, the degree to which their needs were met, and their overall satisfaction with services accessed during their time at school. See Appendix C for a detailed cross-tabulation table which summarized the frequency of access, degree to which their needs were met, and satisfaction with on-campus services reported by the pilot group. The on-campus supports and services accessed included accessibility services ( $n = 7$ ), library services ( $n = 7$ ), mental health services ( $n = 5$ ), academic advising ( $n = 5$ ), and registrar services ( $n = 5$ ), student success services ( $n = 4$ ), department or faculty-based services ( $n = 4$ ), financial aid & awards ( $n = 4$ ), physical health services ( $n = 3$ ), tutoring ( $n = 3$ ), campus security ( $n = 2$ ), ASD mentorship programs ( $n = 1$ ), the ombudsperson ( $n = 1$ ), human rights and equity services ( $n = 1$ ), Indigenous student services ( $n = 1$ ), and the campus meal plan ( $n = 1$ ). None of the participants reported accessing first-generation student services or international student services.

The majority of the participants who accessed services reported that their needs were met and that they were satisfied with the services provided. However, there were some notable exceptions. Specifically, two participants reported their needs were somewhat met and not met, and one participant reported that they were somewhat dissatisfied with campus security services. Two participants reported that their needs were somewhat met, and one participant reported that they were somewhat dissatisfied with library services. Two participants reported that their needs were somewhat met with student success services. One participant reported that their needs were somewhat met, and they were somewhat dissatisfied with autism-specific services. One participant reported that their needs were somewhat met, and they were somewhat dissatisfied

with physical health services. Two participants reported that their needs were somewhat met, and they were somewhat dissatisfied with mental health services.

Participants also reported accessing services off-campus including autism-specific services (n = 5), mental health services (n = 4), physical health services (n = 2), tutoring (n = 2), and meal delivery services (n = 1). The majority of participants who accessed services reported that their needs were met and they were satisfied with the services received, with some notable exceptions. Specifically, one participant reported that their needs were not met and one participant reported that they were somewhat dissatisfied with mental health services. See Appendix D for a detailed cross-tabulation table which summarized the frequency of access, degree to which their needs were met, and satisfaction with off-campus services reported by the pilot group.

**Summary.** In most circumstances, participants' needs were met and they were satisfied with the supports and services accessed during their time at school. Interestingly, although several recommendations related to one of the services accessed most often by pilot participants, accessibility services, some recommendations also related to services reported as accessed by the fewest number of participants.

**Recommendations.** Participants identified several potential changes that may have been helpful for them or may make the post-secondary experience better for Autistic students in response to one qualitative question. Although responses in this area were less robust, four distinct themes emerged through thematic analysis of participant responses. The relationships between these themes are represented in the thematic map presented in Figure 3-7. A word cloud generated from participant responses is presented in Figure 3-8.

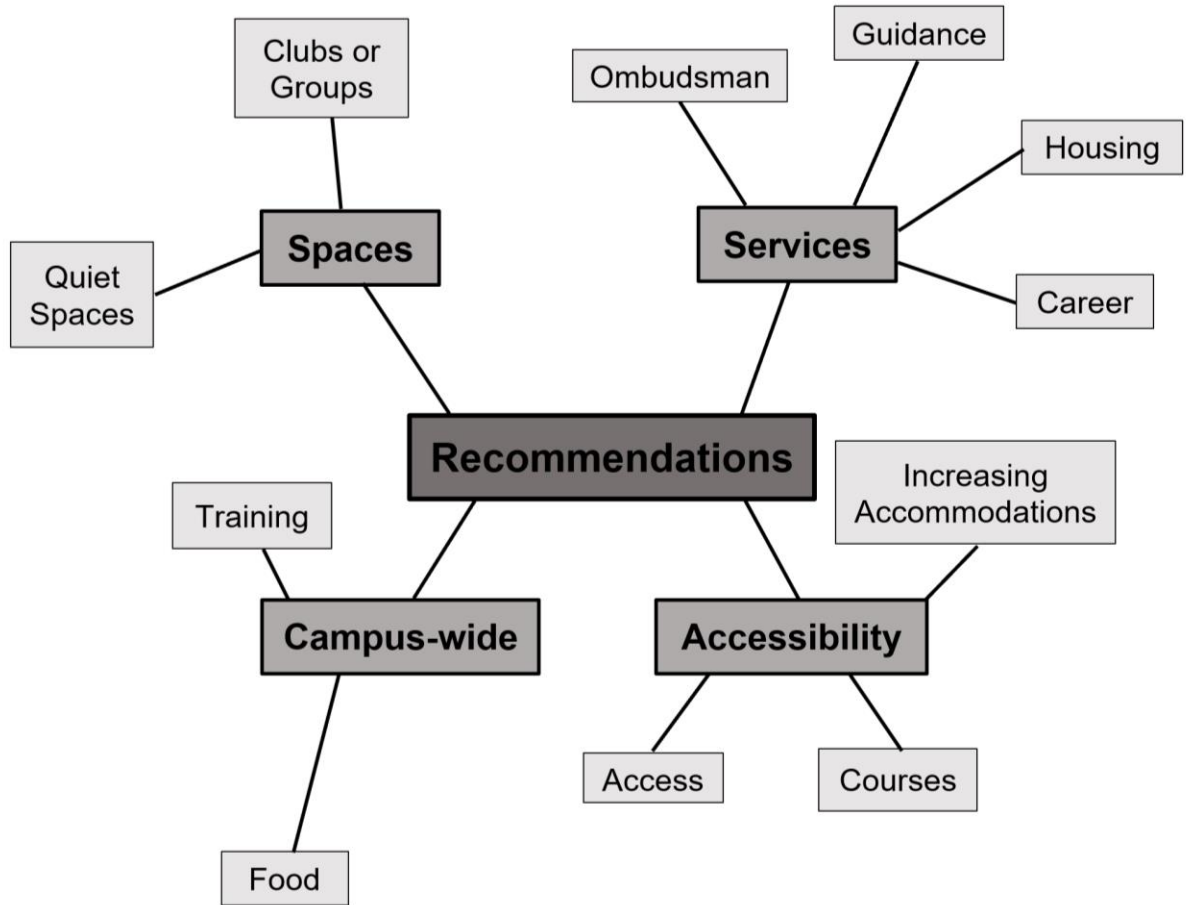


Figure 3-7. Thematic map of analysis completed for participant responses related to recommendations for improving the post-secondary environment.



**Spaces.** The theme of spaces emerged through analysis of participant feedback which focused on physical or social settings in the campus environment.

The sub-category of *quiet spaces* related to rooms or areas on campus that were designated as “sensory friendly” or spaces with reduced stimulation. Participants expressed a desire to take breaks as needed on campus and access a dedicated quiet space. One participant noted that “having quiet spaces to be more secluded to "de-stress" would have been helpful.”

The sub-category of *clubs or groups* related to autism- or disability-specific groups. One participant expressed a desire for more campus clubs, groups, courses, and programs for individuals with ASD. Another participant expressed a desire for groups with an emphasis on disability, specifically an “on-campus activist group focused on disability justice.”

**Accessibility.** The theme of accessibility related to recommendations for increasing accessibility on campus, both at an individual level and more broadly.

*Increasing accommodations* was the first sub-category which emerged through thematic analysis. Several participants reported that additional academic accommodations would have been helpful and that the level of academic accommodation did not meet their needs. Additionally, it was reported that instructors were not always open to providing academic accommodations, which further limited access. One participant shared that “proactively offering new/additional accommodations” would have been helpful. Another participant stated that a change that would have been helpful was “[m]ore accommodations, if you've noticed from my answers earlier, they weren't willing to give much to me.”

The sub-category of *courses* related to recommendations that would increase the accessibility of courses in general. This sub-category included recommendations to support the implementation of academic accommodations and recommendations that would reduce the need



for accommodations. Specifically, one participant identified increasing communication between course instructors and accessibility advisors to support understanding and consistent implementation of academic accommodations. The participant noted that:

“one thing that arose regarding my taking my mid terms was that a couple of profs had different interpretations regarding this. One prof had me take a mid-term in a small private room with another student who was in the same class as me and waited in their office a couple of floors above us watching the time and we then went up and handed in our tests while another one was in the same room with me to supervise me as I took my test.”

Another participant suggested that courses should include “ [l]ess reliance on memorization, or allow cheat sheets,” and instead, “[t]each how to organize and find data.” This participant was a recent graduate who reported using more practical skills, such as bookmarking relevant resources, instead of memorization in their current employment setting.

The sub-category of *access* emerged from recommendations for improving accessibility on campus overall. Specifically, one participant identified that prompt elevator and automatic door repair, as well as additional digital clocks on campus, would be helpful.

**Services.** The theme of services emerged through analysis of participant responses focusing on recommendations for changes or additions to services offered on campus.

The sub-category of *ombudsman* related to the process for providing feedback to colleges and universities. Specifically, it was suggested that all campuses should have a mechanism for providing “compliments and complaints” and that the process for addressing complaints should be timely, straightforward, and clearly communicated. One participant noted that “[a]ll colleges should have independent ombudsman to deal with complaints.”

The sub-category of *housing* emerged through analysis of the response of one participant focusing on off-campus housing. This participant expressed a desire for campus services that would help students to find suitable housing off-campus. Specifically, “services to help teach about finding good living spaces other than residence in or around campus as well as next steps such as rental agreements.”

The sub-category of *career* related to services for graduating and graduated students. One participant provided a recommendation for a service on campus providing:

“help creating and maintaining a daily routine around applying for jobs. Also help with the fact that having to think or talk about myself or the future (a necessary part of job searching) is a major anxiety/depression trigger for me and has been for most of my life. Advice on following up after job fairs, including editable email templates to send people, would also be helpful. Hearing about the importance of networking, without being provided with very specific and actionable advice on how to achieve it, is frustrating.”

It was suggested that this support should offer guidance related to communication skills, such as networking and “following up after job fairs, including editable email templates to send people.”

The sub-category of *guidance* emerged through the analysis of a response from one participant. This participant expressed a desire that “there were areas where you can just talk to people and ask advice with no bias.”

**Summary.** Overall, recommendations for change identified by this pilot group aligned closely with the areas of need identified, as well as relating to the supports and services accessed most and least by the pilot participant group.

## Discussion

Overall, the preliminary findings of this pilot survey provided important insights into the post-secondary experiences of Autistic students in Ontario. As research in this area is limited, the experiences reported by this small group of individuals with post-secondary experiences contributed meaningfully to research in this area. Notably, this study focused on post-secondary adjustment, the self-reported areas of strength and need (i.e., barriers and limitations), supports and services accessed, and recommendations relevant to the post-secondary setting.

**Post-secondary adjustment.** Post-secondary adjustment, as depicted by the SACQ scores, was somewhat lower than expected in this pilot participant group. Although the research supporting a meaningful comparison is quite limited, Wise (2015) reported the mean scores for current Autistic post-secondary students were within the average range for all subscales and the full scale. In this study, the mean scores were within the average range for only two subscales: academic adjustment and personal-emotional adjustment. However, it was consistent with the strengths and challenges identified by participants and the limited research literature focusing on college adjustment and individuals on the autism spectrum, that this pilot sample reported the highest adjustment scores within the academic adjustment subscale, and the lowest adjustment scores within the social adjustment subscale (e.g., Wise, 2015). Relatedly, Trevisan and Birmingham (2015) found that Canadian undergraduate students demonstrating ASD characteristics scored lower when compared to peers who did not demonstrate ASD characteristics on academic adjustment, social adjustment, and personal-emotional adjustment, with significant differences reported on the academic and social adjustment subscales. The limited body of research on the adjustment of Autistic post-secondary students, particularly in the Canadian context, merits further investigation with a larger sample.

**Strengths and needs.** Similar to previous research, academic skills and competencies were identified as an area of strength (e.g., Anderson et al., 2018, Gelbar et al., 2015; Van Hees et al., 2015). In addition to the thematic analysis results, the words *study*, *work*, *research*, *writing*, *lecture*, and *knowledge* were prominent in the word cloud generated. Specifically, the sub-category of critical thinking skills, the strong memory reported within the sub-category of knowledge, and the proficiency with technology reported within the sub-category of competence which emerged through thematic analysis were consistent with the existing research (e.g., Anderson et al., 2018; Van Hees et al., 2015). Additionally, attention to detail was categorized as a personal strength within the sub-category of organization in this study. Although this area of strength was also prominent in the study conducted by Anderson and colleagues (2018), being detail-oriented was described as an academic strength. This difference may be indicative of deviation in participant responses or deviation in analysis and interpretation. The personal strength of sociability reported by participants in this study was somewhat consistent with previous research. Although not commonly reported in research, Van Hees and colleagues (2015) found that participants identified their sincerity and willingness to listen as areas of personal strength that benefitted them in relationships. Similarly, participants in this study identified patience, kindness, and an ability to communicate with others as strengths. Diverging from previous literature, participants also identified perseverance as a personal strength, which included skills in the areas of self-advocacy and determination. Previously self-advocacy and disclosure have been identified as areas of skill deficit or discomfort for post-secondary students on the autism spectrum (e.g., Anderson et al., 2018; Van Hees et al., 2015). Although limitations related to advocacy skills and discomfort with disclosure also emerged through the analysis of

participant responses, the dichotomy of this sentiment in the results may suggest a trend towards skill development.

Similar to the areas of strength identified, the areas of limitation were generally academic. This somewhat diverges from the literature where academics were often identified as an area of strength, and social competencies were identified as a prominent area of challenge (e.g., Gurbuz et al., 2019; Jackson et al., 2018). Several areas of limitation identified were also consistent with the literature. Participants reported that they had experienced challenges related to social connections, study skills, and navigating group work (e.g., Cullen, 2015; Gelbar et al., 2015; Jackson et al., 2018; Ncube et al., 2019). Related to social connections, the words *people* and *socialize* were also prominent in the word cloud generated. Study skills emerged through thematic analysis as an area of particular challenge but was less prominent in the word cloud. Additionally, participants reported experiencing personal challenges related to mental health, specifically anxiety, depression, and stress, despite only the word *anxiety* present in the word cloud. These areas were also identified by participants in the study conducted by Jackson and colleagues (2018), where 75% of participants reported experiencing some form of lifetime suicidal behaviors, a topic area that was not noted, reported, or directly examined in the current study.

The barriers that emerged through thematic analysis were also generally consistent with those identified in the literature and provided insight into the similarities and differences in the current Canadian context. It was expected that participants would identify access and ableism as barriers in the post-secondary setting as accessibility and academic accommodations have been discussed prominently in the research literature (e.g., Anderson et al., 2018; Barnhill, 2016; Smith, 2007; Vincent et al., 2017). In addition to the relevant thematic analysis results, the words

*access*, *accessible*, and *understand* were prominent in the word cloud generated. Other barriers identified, such as navigating transit and employment after graduation, have also been identified in research (e.g., Anderson et al., 2018; Cullen, 2015). One additional area for consideration that emerged through thematic analysis, was navigating the learning management system, as part of the sub-category of navigating school. As colleges and universities increasingly utilize technology, it is imperative to ensure that these resources are accessible and that supports are available to assist students to transition to and navigate these systems. These findings highlight important considerations for the development of supports and services on campus. It is also important to note that these barriers and challenges may not be experienced by all post-secondary students with ASD. One participant reported that they did not experience any challenges or barriers, while the limitations reported by each participant also differed.

Overall, this depiction of participant strengths and challenges, as well as the barriers encountered in the post-secondary setting highlighted several considerations for the development of specialized supports for post-secondary students on the autism spectrum. The dichotomous sentiments reported, including social strengths and challenges, comfort and discomfort with self-advocacy, and the lack of concerns related to personal or academic limitations reported by one participant, highlight the importance of individualized and responsive supports for Autistic post-secondary students. Although the development of supports and services should be grounded in the research, they should be provided on a case-by-case basis with consideration of relevant individual needs (Taylor, 2005; Smith, 2007).

**Supports and services.** The supports and services accessed by the greatest number of participants were consistent with the experiences and needs highlighted in the qualitative analysis. For example, mental health emerged as an area of need and personal limitation through

the thematic analysis process in this study. Additionally, 11 of 12 participants reported experiencing at least one mental health concern. This was also reflected in services accessed, with five participants reporting that they had accessed on-campus mental health services and four reporting that they had accessed off-campus mental health services. Participants accessing mental health services on-campus reported that their needs were mostly or somewhat met by the services provided, while half the participants who accessed services off campus reported that their needs were met. Participants generally reported moderate levels of satisfaction with services on- and off-campus, suggesting that there is room for improvement and providing a direction for future research.

Other supports and services on campus identified as accessed by the greatest number of participants included library services, academic advising, and registrar services. These supports and services were not often discussed in the research literature. As all students would interact with registrar services during course registration each term, Registrar services are an important area for consideration in research and practice. The importance of academic advising was emphasized by Shmulsky, Gobbo, and Donahue (2015) in reviewing the outcomes of a post-secondary transition program for students with ASD in the US. Additionally, although it was unclear if participants' interactions with library services were related to accessing the space or seeking research-related guidance, and this service area was not identified by participants in the qualitative items, the results suggest that both the physical space and associated services are important to consider in future research and on campus. The library was also identified in previous research conducted by Madriaga (2010) as a space that was inaccessible, crowded, and too noisy by post-secondary students with ASD. The number of participants accessing these services highlights areas where further examination through research, as well as areas where

additional training and consideration relevant to Autistic post-secondary student needs may be beneficial. This exploration may be particularly important for library services where two participants reported that their needs were not met with one of those participants also reported that they were somewhat dissatisfied with services received, and for academic advising where two participants reported that their needs were only somewhat met by the services provided.

The services and supports that were accessed by the fewest number of participants were generally services relevant for specific students or under specific circumstances. For example, although first-generation student services, international student services, and Indigenous student services may offer supports for all students, these services primarily provide support for a specific student population. Additionally, one student reported accessing the campus ombudsperson and one reported accessing human rights and equity services on campus. As both services help students to navigate significant concerns related to diversity, equity, and human rights, this suggests that few students have experienced these specific concerns during their time at school. Further, participants who accessed these services reported that their needs were met and they were very satisfied with the support provided. However, the experiences of all participants may not have been as positive, as the ombudsperson emerged as a sub-category within the theme of services related to recommendations for campus. Participants identified that the process for addressing complaints should be clear and independent. Lastly, use of the campus meal plan and ASD mentorship program were reported by one participant each. However, it is unclear if this access related to a lack of availability, lack of interest, or other factors, as they were not identified in qualitative responses. Notably, half of the participants who completed Part C reported accessing autism-specific services off campus, with all reporting that their needs were



met or mostly met, and that they were very satisfied or somewhat satisfied, which suggests an openness to supports specific to ASD when available, effective, and appropriate.

Qualitative survey items examining service use facilitated the identification of additional relevant supports and services, specifically, life coaching and finance services. Interestingly, although participants were provided with the opportunity to identify other supports and services accessed in the quantitative questions focusing on service use, zero participants reported accessing other services in this section, suggesting these supports may not be notable enough to differentiate. As experiences with supports and services were explored using qualitative and quantitative methods, the results facilitated a direct comparison of the strengths and limitations of these methods. As expected, participant responses to qualitative items provided additional details, such as reasons for satisfaction or dissatisfaction. However, participants reported on their experiences with a greater number of supports and services when options were presented in a quantitative format. Consistent with the strengths of each format, qualitative questions supported greater response depth, while quantitative questions supported greater response breadth (Yardley & Bishop, 2017). These results demonstrate the value of mixed methods in research.

**Recommendations.** Recommendations identified focused primarily on two areas: training for faculty and staff and increasing accessibility at the course and campus level. In support of the thematic analysis results, the words *accommodations*, *accessible*, *training*, *staff*, and *professor* were prominent in the word cloud generated. Specialized training to increase knowledge and understanding of ASD for faculty and staff was also previously identified as an important future direction for research and practice (e.g., Alcorn MacKay, 2010; Anderson et al., 2017; Cullen, 2015; Vincent et al., 2017). Studies focusing on post-secondary students on the autism spectrum have also identified gaps in accessibility and accommodations on campus (e.g.,

Barnhill, 2016; Smith, 2007). Recommendations related to service areas such as the campus ombudsman, housing, career, and guidance services have not been commonly reported in the research but may represent other important areas for consideration in providing holistic support. Recommendations related to spaces on campus were consistent with the literature. For example, 97% of participants in a study conducted by Gelbar and colleagues (2015) reported that they preferred to spend time in quiet spaces on campus. This statistic further supports the recommendation from pilot participants to provide quiet and “sensory-friendly” spaces on campus. The recommendation for relevant clubs and groups was consistent with existing research (e.g., Cullen, 2015). These spaces and opportunities for social connection may be particularly important for commuter students.

**Participants.** Discussion of the results must also consider the representativeness of the participant sample. In this study, although participants were not selected randomly, participant demographic characteristics aligned with the Canadian Autistic post-secondary population at large. Specifically, recent research has suggested that there is a greater proportion of gender variance among individuals on the autism spectrum as compared to the general population (Dewinter, De Graaf, & Begeer, 2017; Glidden, Bouman, Jones, & Arcelus, 2016; van der Miesen, de Vries, Steensma, & Hartman, 2018). Additionally, an increased proportion of individuals with ASD report non-heterosexual attraction as compared to the general population (Dewinter et al., 2017; George & Stokes, 2018). Therefore, the variance in gender identity and sexual orientation reported by this participant group was expected. Additionally, as expected with any recent sample of post-secondary students attending college or university in Canada, participants reported identifying with a diverse range of cultures, creeds, and ethnicities (Universities Canada, 2019; Usher, 2019). Specifically, fostering and supporting diversity and

inclusion on campus was identified as a priority for Ontario universities (Council of Ontario Universities, 2021). Although the age of the participant sample was older on average than one may expect, it is important to note that several participants had completed or were not currently attending studies. Additionally, it is known that individuals with ASD may delay starting post-secondary studies (Anderson et al., 2018; Shattuck et al., 2012). Autistic post-secondary students are also known to experience increased physical and mental health concerns as compared to peers (McLeod et al., 2019; Jackson et al., 2018; White, Ollendick, & Bray, 2011). Consistent with the concerns reported by the pilot participants, anxiety, ADHD, and learning difficulties are commonly experienced by individuals on the autism spectrum without intellectual disability (Anderson et al., 2018; Bellini, 2016; Mayes & Calhoun, 2006; McMorris et al., 2019; Hofvander, 2009).

**Strengths.** There were several important strengths of this study. First and foremost, this study was the first to focus on the self-reported strengths, experiences, and needs of Canadian Autistic post-secondary students. Research examining self-reported strengths of Autistic post-secondary students has been identified as an important area for further study (e.g., Anderson et al., 2018; Schindler, Cajiga, Aaronson, & Salas, 2015). Additionally, the inclusion criteria supported increased generalizability as a formal ASD diagnosis was not required, in contrast to most current research (e.g., Anderson et al., 2018; Koegel et al., 2013; MacLeod & Green, 2009; Vincent et al., 2017). Further expanding the existing research and addressing an identified gap, this sample also included a participant who had stopped attending studies (Gelbar et al., 2015).

Another important strength of this study was that participants were compensated for their time. Consistent with a PAR approach, this compensation valued the time and expertise of the participants. Additionally, this group of pilot participants was highly representative of the target

population and included a range of ages, geographic locations, programs attended, and identities. This increased diversity was facilitated by the online recruitment methods and varied geographic locations of the steering committee members, as well as the web-based survey; it is unlikely that such a diverse range of participants would have been accessed with location-based recruitment or in-person research methods.

**Limitations.** Although still larger than and comparable to much of the published literature focusing on the self-reported experiences of Autistic post-secondary students (e.g., Berry, 2018; Casement et al., 2017; Cox et al., 2015; LeGary, 2017; Vincent et al., 2017) the sample size for this study was small, which reduced the potential generalizability of the findings. Further, as recruitment for this study was not random and participants received compensation for participation, the generalizability of the findings may be further reduced. However, as the aim of this study was to gather preliminary findings and the aim of the larger project was to solicit feedback to refine the survey, the reduced generalizability was not a substantial concern.

**Future directions.** Several future directions for research were delineated in reviewing the results. Specifically, it was identified that post-secondary campuses may benefit from providing specialized training for staff and faculty relevant to their roles supporting students with ASD, while Autistic students may benefit from access to quieter and less crowded spaces on campus. This thesis identified which specific services are being accessed, and not accessed, by students on the autism spectrum, as well as which services may not be meeting their needs, such as academic advising, library services, and mental health services. Further research is needed to determine specific recommendations, benefits, and barriers relevant to these spaces and services. In future, the development of specialized and individualized supports and services for students

with ASD should utilize a strengths-based approach with consideration of the barriers and challenges that may impact the post-secondary experience for an Autistic student.

**Conclusion.** To maximize the impact and efficacy of best practices and recommendations to support the success of post-secondary learners, changes should be driven by the recommendations for improvement identified by Autistic learners, with consideration of the known strengths, limitations, and patterns in the use of supports and services reported by post-secondary students with ASD.

### Chapter 4: Study 3

This study focused on feedback provided by pilot participants who had completed a survey exploring the strengths, experiences, and needs of Autistic post-secondary students developed using a PAR approach. An exploration of efficacy and effectiveness through comparing qualitative and quantitative methods was reported in addition to discussion of strengths and weaknesses of this pilot survey measure identified.

#### **Introduction**

It is important to seek the perspectives of individuals with lived experiences in developing research, theory, and practice. In conducting research, all decisions should be evidence-based. When using a PAR approach, these decisions should be guided by relationally acquired knowledge in addition to the research literature.

**Survey testing.** As described by McCalman and colleagues (2017), survey testing completed by individuals with lived experiences is an important step in research using a PAR approach to ensure that the survey items developed are relevant and comprehensible. However, research exploring the testing of surveys developed using a PAR approach is limited, particularly with post-secondary students on the autism spectrum. Notably, Sarrett (2018) reported soliciting feedback on a survey developed to explore the post-secondary experiences of individuals on the autism spectrum from two Autistic self-advocates, as well as one academic and one non-academic individual. Although this study reported that feedback was obtained regarding comprehension, accessibility, design, length, and other relevant aspects, the process for review and analysis of feedback guiding survey revision was not discussed in detail.

**Participants.** In conducting survey testing using a PAR approach the individuals participating in testing should be representative of the individuals who will be completing the

survey (e.g., McCalman et al., 2017). It is recommended that survey usability testing include individuals who are representative of the target population (Geisen & Bergstrom, 2017; Singer & Ye, 2013). Further, participants who were not involved in the development of the specific survey measure may provide novel and accurate insights regarding appropriateness and comprehension.

***Incentives.*** A recent report published by the Higher Education Quality Council of Ontario found that providing a monetary incentive for participation in an online test yielded higher rates of participation in a sample of post-secondary students (Peters, Hall, & Skinkle, 2017).

Compensating participants for completing online survey measures is known to increase the completion rate, with vouchers more effective than lotteries with longer questionnaires in particular (Deutskens, De Ruyter, Wetzels, & Oosterveld, 2004). Research has yielded mixed or inconclusive results concerning the impact of providing incentives on response quality for online measures (Görizt, 2006 Peters et al., 2017; Singer & Ye, 2013).

***Response quality.*** An assessment of response quality has often been used in the literature to compare outcomes related to specific dependent variables in research methodology, such as the provision of incentives and survey length (e.g. Peters et al., 2017; Singer & Ye, 2013; Simmons & Wilmot, 2004). One such metric often used to assess response quality is missing data, or item nonresponse (e.g., Simmons & Wilmot, 2004; Galesic & Bosnjak, 2009). Previous studies focusing on online surveys have also considered response accuracy and speed as indicators of data quality, with greater response speeds indicative of reduced response quality (e.g., Deutskens et al., 2004; Peters et al., 2017; Revilla, 2016)

***Feedback.*** Researchers must also select mechanisms for feedback with intention and consideration of the resources available. Methods for obtaining feedback during user testing identified by Qualtrics XM (2020) included lab testing, remote testing, surveys, intercepts or

popup windows, and focus groups. It was noted that while obtaining feedback using a survey is cost-effective and allows a researcher to gather information from a large number of users, it requires reliance on the user's memory and interpretation of their experience.

**Research methods.** Several variations in naming conventions exist in describing the methods used to guide and conduct research. The methods delineated by Creswell and Plano Clark (2011) are often implemented in education research. One such method is the multiphase mixed method design, which combines concurrent and sequential elements within the same study. This research design is considered advanced and often utilized when the program or research objectives cannot be met within a single mixed methods study. These designs are commonly used in multiphase research for program development and evaluation.

**Mixed methods.** The general strengths and limitations of qualitative and quantitative methods have been thoroughly examined and reported in the context of mixed methods research in the social sciences (e.g., Creswell & Plano Clark, 2011; Tashakkori & Teddlie, 2016; Yardley & Bishop, 2017). The literature also provides support for combining qualitative and quantitative methods in research focusing on post-secondary students, including those on the autism spectrum (e.g., Mazzola et al., 2011; Walton, 2016; White, Elias, et al., 2016).

**Measure design.** In developing and refining mixed methods measures, researchers should aspire to explore the subject matter effectively and efficiently. A brief and focused measure reduces issues related to recruitment, break-off, and response quality in online surveys (Galesic & Bosnjak, 2009). Repetition and double negatives should be also avoided in the development of individual survey items (Gideon, 2012). To support increased response quality, expectations related to response quality and length should be communicated clearly (Smyth et al., 2019).



## **Purpose**

The aim of this study was to gather information regarding the strengths and weaknesses of a survey developed through a participatory approach as reported by a group of post-secondary students on the autism spectrum during pilot survey testing to guide further survey revision.

## **Research Questions**

This study explored the following research questions:

1. What was the most efficient and effective methodology for examining the experiences of post-secondary students with ASD using qualitative and quantitative methods?
2. What were the strengths and weaknesses of this survey developed using a PAR approach as identified by this pilot group of post-secondary students with ASD?

## **Method**

The research design used in this study was best described as a multiphase mixed methods design as concurrent and sequential elements were incorporated in the same study (Creswell & Plano Clark, 2011). Specifically, the measure included the presentation of qualitative and quantitative questions concurrently through Parts B and C, followed in sequence by Part D which featured a qualitative emphasis.

**Participants.** This study included 10 participants who self-identified as Autistic, had completed at least one semester of college or university in Ontario, and had completed parts A through C of the survey as described in Study 2. Additionally, one participant who did not meet the eligibility criteria for Study 2 but had completed Parts A through C of the survey due to an error in survey logic was included in this sample, resulting in a total of 11 participants. A summary of participant demographic characteristics is available in Table 4-1.

Table 4-1

*Participant Demographic Characteristics*

Demographic Characteristics	Number of Participants (%)
<i>Age</i>	
21	2 (18.18%)
23	2 (18.18%)
24	2 (18.18%)
25	1 (9.09%)
27	1 (9.09%)
28	1 (9.09%)
31	2 (16.67%)
<i>Gender Identity</i>	
Male	6 (54.55%)
Female	2 (18.18%)
Non-Binary	1 (9.09%)
Trans Masculine	1 (9.09%)
Unsure	1 (9.09%)
<i>Sexual Orientation</i>	
Aromantic asexual	1 (9.09%)
Asexual	2 (18.18%)
Bisexual	4 (36.36%)
Demisexual	1 (9.09%)
Heterosexual	1 (9.09%)
<i>Physical Health Concerns</i>	
Allergies	2 (18.18%)
Asthma	3 (27.27%)
Cellulitis	1 (9.09%)
Graves' disease	1 (9.09%)
Irritable bowel syndrome	1 (9.09%)
Mobility or dexterity disability	1 (9.09%)
None	4 (36.36%)
<i>Mental Health Concerns</i>	
Anxiety	10 (90.91%)
Attention deficit hyperactivity disorder/attention deficit disorder	6 (54.55%)
Depression	3 (27.27%)
None	1 (9.09%)
<i>Learning Difficulties</i>	
Math	1 (9.09%)
Non-verbal	4 (36.36%)
Non-verbal cues	1 (9.09%)
Reading	3 (27.27%)
Reading comprehension	1 (9.09%)
Verbal	1 (9.09%)
Writing	2 (18.18%)

None	2 (18.18%)
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In describing their identity in relation to culture and ethnicity, participants self-identified as Canadian, Chinese, Indian, African, Asian, Franco Ontarien, Vietnamese, White, and an Aspergirl, with three participants identifying with more than one group. In describing their creed, faith, or religious identities, participants self-identified as Atheist, Buddhist, Christian, Secular, and Roman Catholic. The majority of participants (54.55%, n = 6) did not identify with any creed, faith, or religion.

In disclosing physical health concerns three participants (27.27%) reported experiencing more than one physical health concern, four participants (36.36%) reported experiencing one physical health concern, and four participants (36.36%) reported no physical health concerns. In disclosing mental health concerns, seven participants (63.64%) reported experiencing more than one mental health concern, four participants (36.36%) reported experiencing one mental health concern, and one participant (9.09%) reported no mental health concerns. A total of nine participants (81.82%) reported experiencing learning difficulties, with three participants (27.27%) reporting difficulties in more than one area. Participants' most recent post-secondary experiences were summarized in Table 4-2.

Table 4-2

*Participant Post-Secondary Experiences*

Student Status	School	
	College	University
Currently Enrolled	1 (9.09%)	3 (27.27%)
Graduated	4 (36.36%)	2 (18.18%)
Not Enrolled, Planning to Return	-	1 (9.09%)

**Recruitment.** Recruitment for this study was not random. The approach used was most consistent with critical case non-random sampling (Onwuegbuzie & Collins, 2007). Participants who had completed Parts A through C of the survey were asked to provide feedback.

**Compensation.** Participants received compensation for participation in the form of an electronic transfer of funds or cheque provided by mail. Participants received 25 dollars for completing Part D of the survey and received 100 dollars total compensation for participation in the pilot survey.

**Consent.** Participants had provided consent for participation in this study as part of the survey pilot. As it is paramount in research that consent is informed and ongoing, participants were informed that completing the last part of the survey was optional.

**Procedure.** Participant responses to the questions and Parts B and C of the survey were compared to assess relative benefits and limitations. This comparison included specific feedback solicited through Part D as well as measures of data quality, including duration and nonresponse. Participants feedback on all aspects of Parts A through C provided in Part D informed assessment of the measure's strengths and weaknesses overall.

**Survey.** Parts B and C were presented to participants in sequence. Both parts focused on the topics of spaces and extracurriculars, supports and services, and academic accommodations. These topics were examined using a qualitative emphasis in Part B and through quantitative questions in Part C. Participant responses in relation to these topics were explored in Study 2. The estimated completion time identified by Qualtrics XM software was 1 hr 12 min for Part A, 20 min for Part B, and 19 min for Part C, for a total of 1 hr 51 min for Parts A through C.

Following the completion of Part C, each participant received the link to access Part D via email. This email included an attachment, which included instructions for completing Part D

and a summary of survey topics (see Appendix E). Part D included all questions from previous sections of the survey (Parts A – C) with space to provide feedback after each question, as well as separate open-ended questions requesting broader feedback on the survey content, suggestions for improvement, and future recruitment and dissemination. In Part D, participants were asked directly about their preference between Part B and Part C.

*Analysis.* The comparison conducted between Parts B and C incorporated qualitative and quantitative methods in analyzing survey data and participant responses. This analysis included an interactive level of interaction as the qualitative and quantitative strands were mixed prior to the final interpretation (Creswell & Plano Clark, 2011). For example, participant responses to qualitative and quantitative responses focusing on the same topic area were analyzed together to examine missing topics and response options. The analysis of participant feedback provided in Part D used qualitative methods, specifically thematic analysis (Braun & Clarke, 2006).

*Comparative analysis.* Preferences between Part B and C reported by participants were analyzed using a common mixed methods approach where qualitative results were transformed through coding procedures to produce a quantitative count (Fetters, Curry, & Creswell, 2013).

Response speeds were analyzed to assess efficiency using IBM SPSS Statistics (Windows, Version 26.0; IBM Corp., 2019) by entering the survey duration in seconds as provided by Qualtrics XM Software (Qualtrics, 2020) for survey Parts A, B, and C. The compute variable function was used to transform duration in seconds to duration in minutes. The distribution and normality of these variables were assessed using descriptive statistics. First, data cleaning procedures were conducted as required to identify and remove outliers, after which the distribution and normality of each variable was assessed again. Specifically, the explore function was then used to produce descriptive statistics and a 1-D boxplot for each variable to assess the

distribution and normality. Extreme scores and outliers were identified through review of the 1-D boxplot. When extreme scores and outliers were present, the relevant duration variable was recoded into a different variable where extreme scores and outliers were replaced by system-missing scores. The explore function and recoding process were repeated as needed until no outliers were identified.

The proportion of missing data, or nonresponse, was used to assess effectiveness for Parts B and C through a manual comparison with Microsoft Excel (Microsoft Office 365 MSO, Version 2008; Microsoft Corporation, 2020) using the complete data set for each part of the survey exported from Qualtrics XM Software (Qualtrics, 2020). Data cleaning procedures were conducted to remove any variables that did not require a participant response, such as survey items providing an opportunity to exit the survey. A detailed review of all responses was conducted to identify any items that would not have been presented due to survey logic. The cells associated with these responses were marked as “not missing.” Additionally, as separate columns were produced for each item listed in matrix-style questions in Part C, the group of columns associated with each question was reduced to one column. For questions where participants were asked to skip any rows that did not apply to their experiences, no option was provided to indicate that the options did not apply to the participant. Therefore, it was assumed that participants had not experienced this topic area and blank cells were also marked as “not missing.” Responses identifying that the item did not apply were counted as a response. The COUNTA and COUNTBLANK functions were used to assess the total number of cells and the number of cells with missing data for each participant in Parts B and C. The number of cells with missing data was then divided by the total number of cells to determine the proportion of nonresponse for each participant. The AVERAGE function was used to calculate the mean

proportion of nonresponse for each part of the survey. The ranges for Parts B and C were visually assessed.

A comparison of participant responses for Part B and Part C was conducted using qualitative methods to highlight additional considerations relevant to the effectiveness of quantitative and qualitative methods elucidated through the pilot survey data. Participant responses from Part B were reviewed using qualitative methods to identify additional topic areas or specific examples that were not presented in quantitative survey items in Part C (e.g., spaces, supports, services, or academic accommodations). Participant responses to the question “Is there anything you wanted to share with us that you haven’t had an opportunity to talk about yet? If yes, please let us know what we missed below” in Part C were also incorporated in the analysis of missing topic areas and reported qualitatively. Both broad and specific topic areas identified through this review were used to generate a list of missing topic areas. Responses from Part B were also analyzed using qualitative methods to identify response characteristics that were not present in responses for Part C. Additionally, responses to questions in Part C where participants were provided opportunities to identify additional relevant examples were reviewed and summarized.

*Survey feedback.* Participant responses for Part D of the survey were analyzed using thematic analysis (Braun & Clarke, 2006) to identify main overarching themes and sub-themes relevant to survey strengths, weaknesses, and suggestions for improvement. The qualitative analysis process followed the phases of thematic analysis described by Braun and Clarke (2006), specifically: (a) familiarizing yourself with your data; (b) generating initial codes; (c) searching for themes; (d) reviewing themes; (e) defining and naming themes; and (f) producing the report. These themes were further elucidated by excerpts selected from participant responses. Consistent

with the recommendations of the American Psychological Association (2019) regarding gender and bias-free language, as participants had not reported their pronouns, the singular “they,” or “their” in association with participant response excepts. This also served to protect participant privacy and confidentiality within the small sample of pilot participants.

To support increased familiarity with the data, participant responses for Part D were exported to a spreadsheet in Microsoft Excel (Microsoft Corporation, 2020). First, all participant responses were reviewed in full, after which data cleaning procedures were conducted to remove columns where feedback was not provided. This cleaned data set was reviewed in detail and all cells including participant feedback were highlighted. A second review was conducted for validation purposes. To generate an initial list of codes, as outlined by Braun and Clarke (2006), participant responses providing survey-related feedback were reviewed. Through this process, distinct topic areas and interesting features of the data were noted. This list was recorded in a document with Microsoft Word (Microsoft Office 365 MSO, Version 2008; Microsoft Corporation, 2020). The process of searching for themes, the third phase of thematic analysis, included reviewing the list of initial codes (Braun & Clarke, 2006). A list of candidate themes was generated by collating initial codes into candidate themes to produce a thematic map in table format. These candidate themes were later reviewed and refined by moving, combining, and expanding sub-categories to produce increasingly clear, cohesive, and distinct themes. This step was completed with consideration of the initial codes and the data set as a whole. After the development of a satisfactory thematic map, these refined candidate themes were defined and named to produce a more fulsome description of each theme. To facilitate verification of the findings and evaluate the trustworthiness of the thematic analysis process, detailed notes relevant to the thematic analysis process were reviewed by a research assistant who was not a member of



the steering committee or otherwise involved in research; agreement was reached for all themes and sub-categories through peer debriefing (Nowell et al., 2017). These final themes were described in the report produced and provided in the form of a written summary in the results section.

## Results

**Comparative analysis.** When asked “Part B and C of the survey covered similar content in two different ways. Part B asked open-ended questions like these, while Part C included more multiple-choice and rating scale-type questions. Do you have a preference for the type of questions in Part B or Part C?” eight of 11 (72.73%) participants identified a preference for the quantitative questions in Part C, two participants did not clearly identify a preference in their responses, and one participant did not respond. One participant noted that “the rating questions were faster to do and the open end questions could be hard for some people but they were ok for me.” Additionally, two participants reported that the response options and examples presented through quantitative questions were helpful in guiding their responses. However, in addition to participant preference, the efficiency and effectiveness of each survey part must also be examined and considered.

**Efficiency.** The average duration of each survey part was analyzed to provide a report of efficiency, or response effort. On average, participants completed Part A in 58.54 minutes ( $SD = 31.73$ ). Part B was completed in 33.08 minutes ( $SD= 22.24$ ) minutes, on average. Participants completed Part C in 43.98 minutes ( $SD= 45.28$ ), on average. The full survey was completed in 133.89 minutes ( $SD= 86.53$ ), on average. Descriptive statistics are reported in Table 4-3.

Table 4-3

*Participant Completion Time for Survey Sections*

Survey Part	n	Mean (minutes)	SD (minutes)	Minimum (minutes)	Maximum (minutes)	Skewness	Kurtosis
Part A	12	58.54	31.73	13.53	93.38	-0.23	-1.72
Part B	11	33.08	22.24	9.32	68.22	0.58	-1.14
Part C	10	43.98	45.28	5.55	131.02	1.10	-0.15
Total	10	133.89	86.53	33.18	224.28	-0.05	-2.91

Through data cleaning procedures for Part A, one extreme score was identified and removed through recoding. Following analysis of the recoded data, two additional extreme scores were identified and removed, resulting in a data set with distribution that was symmetrical (skewness = -0.23) and platykurtic (kurtosis = -1.72). Data cleaning procedures conducted for Part B identified two extreme scores which were removed. Following analysis of the recoded data, one additional extreme score was identified and removed, resulting in data with distribution that was moderately positively skewed (skewness = 0.58) and platykurtic (kurtosis = -1.14). In cleaning the data for Part C, one extreme score was identified and removed through recoding, resulting in data with distribution that was highly positively skewed (skewness = 1.10) and platykurtic (kurtosis = -0.15). Lastly, data cleaning procedures were conducted three times for the total survey completion time, where one extreme score, two extreme scores, and one extreme score were identified and removed through recoding, respectively. This resulted in a data set with distribution that was symmetrical (skewness = -0.05) and platykurtic (kurtosis = -2.91). It is important to note that participants completed Part B, which emphasized qualitative questions, in less time than Part C, which emphasized quantitative questions. However, efficiency is only one aspect for consideration in comparing qualitative and quantitative methods.

*Effectiveness.* The proportion of missing data, or nonresponse, as well as the presence of specific topic areas and response qualities, were analyzed to assess the effectiveness of each survey part in obtaining data from participants.

*Missing data.* The average proportion of missing responses for questions presented to participants in Part B was 13.27% (range = 0.00% – 48.65%, n = 11), while the average proportion of missing responses for questions presented to participants in Part C was 2.73% (range = 0.00% – 16.36%, n= 10).

*Missing topic areas.* Through review of participant responses in Part B, several topic areas were identified that were not included in Part C. See Table 4-4 for a comprehensive list. Several topic areas that were not addressed in sufficient detail in the survey were also identified in participant responses in Part C. As responses to this question were somewhat limited, thematic analysis was not conducted. Four unique topic areas were identified: non-academic skills gained during post-secondary studies, interest in interpersonal relationships, peer perceptions of ASD and disability, and experiences related to unsolicited offers of support.

Table 4-4

*Topic Areas Reported by Participants in Part B Not Presented in Part C*

Topic areas	Specific topics reported
Spaces	ASD-specific spaces Classrooms Concourse Crematorium Esports arena Gender-neutral bathrooms Hallways Nap room Main entrance Student lounge
Events and activities	Book/music swaps Career and networking events Concerts

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	Movie nights
	Speed dating
	Theatres
Services	Career services
	Public transit
	Life coach
Academic accommodations	Assistive technology
	Proportion of additional time
	White noise

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*Response characteristics.* The comparison of participant responses in Parts B and C also highlighted aspects of responses that were not captured by quantitative survey items, such as attributes that made a space more or less desirable, barriers that prevented access, and specific details describing how services accessed were helpful. Review of Part B also facilitated the identification of responses that did not fully correspond to the question presented, such as identifying accessibility services as an informal support (e.g., peers and family members). In Part C, participants were provided with 11 opportunities to identify other spaces, supports, services, or academic accommodations that were not included in the question presented. Across the 10 participants who completed Part C, a response was entered a total of six times across four different survey items.

**Survey feedback.** Primary feedback themes identified through thematic analysis included formatting, phrasing, topic areas, user experience, and project recommendations. Although all participants provided feedback on the survey in Part D, only eight of 11 (72.73%) participants provided feedback on specific survey items. Five distinct themes emerged through thematic analysis. The relationships between these themes and sub-categories are represented in the thematic map presented in Figure 4-1.

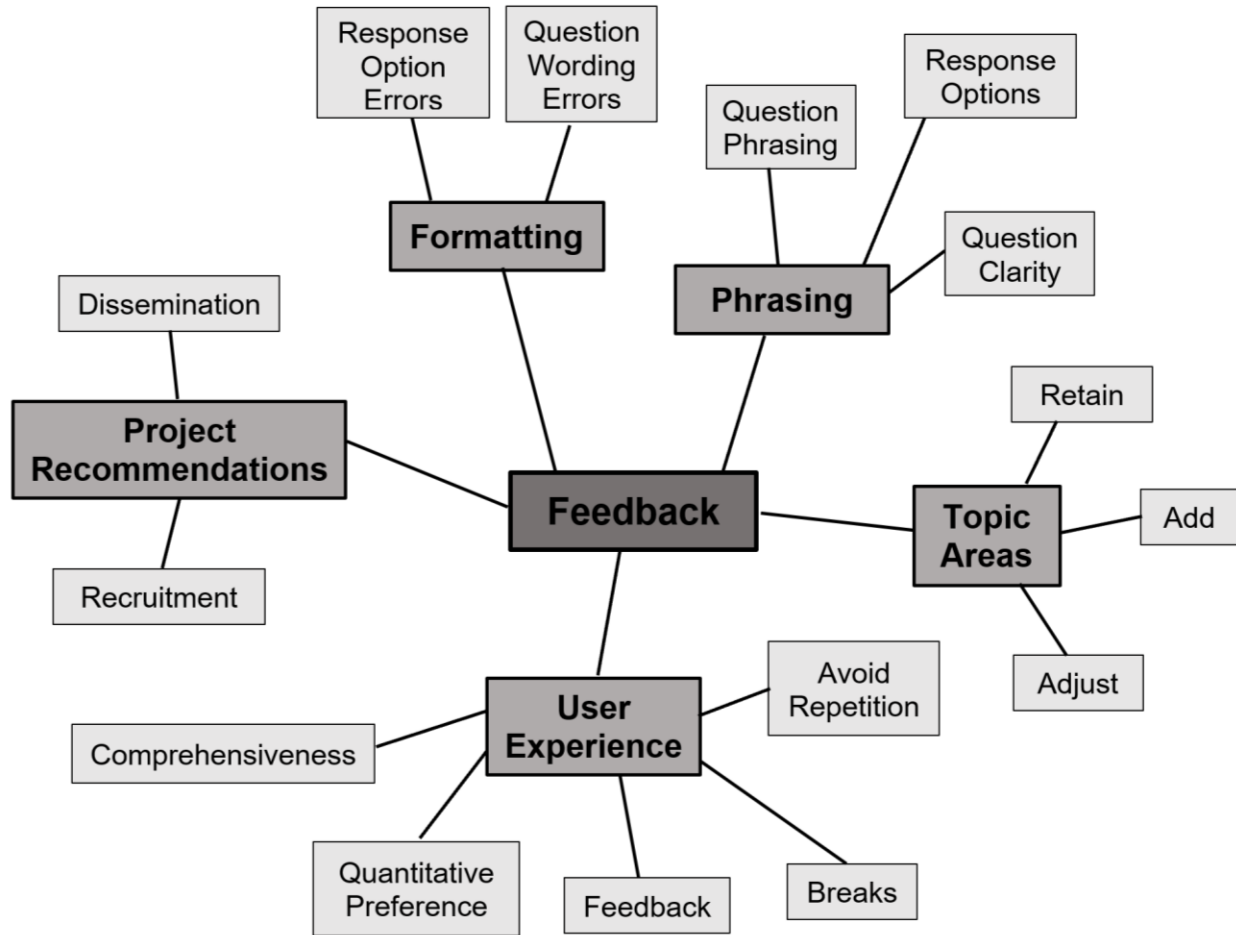


Figure 4-1. Thematic map of analysis completed for participant responses providing feedback on the pilot survey.

**Formatting.** The first theme that emerged related to formatting errors and omissions that had not been identified through previous survey review. Although this theme included a relatively small number of responses, the theme was distinct from other areas of feedback.

*Question wording errors.* One subcategory of this theme related to errors in question wording. Participants identified questions where the tense of the question did not match their experiences. This feedback was often provided by graduates. Although participants were asked to answer questions with consideration of their most recent post-secondary experience, one participant noted that “questions are all written in present tense, making it unclear whether I, a

graduate, should be giving information about my current state or give answers reflecting my time at university.” This feedback was provided regarding the SACQ survey items. One instance where an error in survey logic resulting in a word being omitted in a question was also identified.

*Response option errors.* A subcategory related to response option errors emerged within this theme. Through their feedback, participants identified questions where the selection of response options was impacted by the question format. For example, certain questions where participants were asked to select all response options that applied to their experiences only allowed participants to select one response option. Participants also identified questions where desired response options were not included. For example, one participant identified that “The drop-down menu for “How long have you been looking for a job?” didn't include the options “7 months” or “9 months”, which is particularly frustrating as I have been looking for work for 7 months.”

*Phrasing.* The theme of phrasing emerged in relation to feedback which focused on specific survey items. This theme included the identification of strengths and suggestions for improvement.

*Question clarity.* The first subcategory that emerged within this theme related to questions where the intention was particularly clear or not clear enough. Participants’ feedback highlighted problematic parts which impacted question clarity, exemplified by feedback such as “Double negatives are hard to understand.” One item identified as particularly clear was “Were there specific reasons you didn’t use some of the supports, services, and resources listed on the previous pages?” which provided a list of potential responses as well as a text box where participants could identify any additional information.

*Question phrasing.* Another subcategory that emerged focused on the phrasing of specific questions. Participants identified several survey items that were perceived to be too long or examining too broad a topic. One participant described a question focusing on experiences of living with other people as:

“An important question but so big and overwhelming that I skipped it. Very open-ended questions can be difficult in general, though I understand wanting to avoid leading questions. Breaking this question down into a couple of smaller questions might be helpful.”

Participants also identified specific suggestions for phrasing, such as “instead of avoided try using the words were there any events that made it difficult for your participate.”

*Response options.* An additional subcategory that emerged within this theme related to the relevance and comprehension of response options. Feedback highlighted that participants were not always knowledgeable about specific response options, exemplified by the feedback “[I] was confused by what's department or faculty based services.” One participant provided feedback that questions with potentially unclear response options could be improved by using the hover-over feature to provide a description of the response option, exemplified by the feedback related to one question that “let you hover over answers to get an explanation of what they are, which was great! This should be available for more questions, if possible.” Additionally, participants identified that the option to skip items that did not apply to their experiences was beneficial.

*Topic areas.* The theme of topic areas emerged in relation to subjects viewed as important to include in future iterations of the survey. This theme differed from the previous themes as the theme focused focus on topics broader than specific survey items.

*Retain.* One sub-category of this theme that emerged related to topic areas explored through the pilot survey that were identified as particularly relevant to the post-secondary experience. Specific topic areas identified included the exploration of participant identity in relation to ASD, gender identity, and sexual orientation. In providing feedback on the question exploring gender identity, one participant's feedback stated "[t]hat's good, [I] like the inclusivity."

*Add.* A sub-category related to topic areas that were not explored directly in the survey and should be included in future iterations emerged through analysis. Examples of topic areas identified by participants included transition experiences after post-secondary studies, specific experiences of ableism and discrimination, and "questions on how we feel the education and political system should be reformed to help people with disabilities."

*Adjust.* A third sub-category which emerged related to topic areas that could be further improved or clarified. This sub-category included suggestions for revision of questions exploring experiences before post-secondary studies to capture experiences of individuals "who didn't complete school in Canada/a system where there are IEPs." revision of terms used to describe gender identity to support increased clarity and inclusivity, and revision of the order of presentation for questions exploring formal and informal supports. Additionally, one participant reported that they "wondered if informal support included things and not just people" and identified that objects should be included in questions exploring informal supports.

*User experience.* The theme of user experience related to broader feedback focused on the survey overall.

*Avoid repetition.* The first sub-category that emerged related to repetition. Participants reported that repetitive questions and topic areas should be minimized and avoided wherever



possible. To support survey logic, participants were asked to identify their preferred term related to ASD and their most recent post-secondary experience at the start of each survey section, as well as within the screening survey embedded in Part A. However, one participant expressed feeling “super annoyed with the same questions being asked more [than] once sometimes on the SAME PART.” Some topic areas were also explored in both Part B and C to facilitate the comparison of qualitative and quantitative methods. These specific questions and topics were identified as repetitive through participant feedback. For example, when identifying a preference between Parts B and C, one participant stated that “[m]y preference is for NO REPEATING QUESTIONS, as I said directly in the feedback to those questions, multiple times.”

*Quantitative preference.* Another sub-category which emerged related to participants’ preference for quantitative questions. One participant specifically identified preferring multiple-choice questions. Participants also identified that certain topic areas were best explored through open-ended questions, such as describing individual unmet needs. For example, one participant shared “I prefer open ended questions for when I had first hand experience, and I can really share what it’s like. But when I don’t have that experience, having the multiple choices is helpful.”

*Comprehensiveness.* The subcategory of comprehensiveness related to the depth and breadth of the survey. Participants reported that the survey included a diversity of topics and “asked a lot of important questions.” Although participants also noted that the survey was “very long.”

*Breaks.* In relation to the survey length, the subcategory of breaks emerged. Some participants reported needing to take a break between survey parts. One participant identified the option “to come back to it later” as what they liked most about the survey.

*Feedback.* Providing feedback emerged as a separate sub-category with the theme of user experience. Although the importance of seeking feedback was acknowledged, the format through which feedback was solicited was identified as problematic. In response to a question asking what participants liked least about the survey, one participant identified that “Feedback on every question is too much, and it wasn't clear whether or not I needed to answer them all again, or just provide feedback.” Additionally, when providing feedback on an open-ended survey question, another participant stated that “the design of the question makes it very unclear if I am supposed to be using this text-box to answer the question or give feedback on the question design.”

*Project recommendations.* The final theme which emerged through analysis was related to recommendations for the next steps of this research project. Suggestions for recruitment and dissemination were solicited directly through feedback questions posed to the participants.

*Recruitment.* One subcategory that emerged was related to recommendations for how and where to recruit participants for the Ontario survey. Pilot participants identified two main options for recruitment, namely campus accessibility services and online or in-person communities that were autism-related, such as “autistic-run advocacy groups like A4A, Autistics United Canada, and Autistic Women & Nonbinary Network.”

*Dissemination.* The second sub-category within this theme related to the dissemination of the future survey results and current findings. Overall, participants reported that the findings should be made publicly available and utilized to guide the development policy and recommendations to improve the post-secondary experience for students on the autism spectrum. This sub-category was exemplified by a response from one participant who stated, “I hope that it identifies common barriers and solutions to these barriers to help improve the lives of current and future students.”

## Discussion

Overall, the feedback provided by the pilot participants provided a comprehensive assessment of the efficiency and effectiveness of qualitative and quantitative methods, as well as the strengths and weaknesses of the survey. The feedback highlighted several potential revisions which may enhance the survey measure for future iterations. Importantly, this study also contributed to the body of literature focusing on research measures developed and refined using a PAR approach with individuals on the autism spectrum, which is particularly limited. In supporting the genuine participation of individuals with lived experiences in PAR, it is imperative that consultation, or ideally collaboration, extend beyond the initial development phase. The value and importance of ongoing collaboration were demonstrated in this study.

**Efficiency and effectiveness.** The first research question explored the efficiency and effectiveness of Parts B and C through a comparative analysis. This analysis found a clear preference for quantitative questions was expressed by this group of pilot participants. However, this preference was not without caveats, nor is preference the only metric that should be considered. Although Part C was identified by all participants who indicated a clear preference, the average completion time for Part C of the survey was 10 minutes longer than that for Part B, which suggested that Part C of the survey was less efficient than Part B. As the time to complete the survey was already longer than ideal at over two hours, on average, the aim of reducing the total time for completion is another important consideration. However, the reduced duration may also be indicative of increased response speed and thereby reduced response quality (Peters et al., 2017; Revilla, 2016). Completion time for each part also corresponded loosely with the proportion of nonresponse, a measure of effectiveness. Specifically, the proportion of missing response data was more than 10% greater for Part B, with the difference between maximum

proportions of missing data reported as over 30%. These differences aligned with literature as the known strengths of quantitative measurement include increased completion of survey items as compared to qualitative measurement (Friborg & Rosenvinge, 2013; Griffith et al., 1999; Ivis et al., 1997). Overall, the proportion of missing data and completion time suggest a greater response quality obtained for responses in Part C. However, the results also suggest an added response effort to complete the quantitative questions presented in Part C.

One must also consider other aspects relevant to effectiveness, or response quality in comparing qualitative and quantitative methods. In this study, several experiences were identified as important and relevant by the pilot participants that were not included in Part B of the survey. Although these specific supports, services, and experiences can be integrated into future iterations of the survey, it stands to reason that there may be additional areas considered relevant or important by future survey participants. Although this option was provided in Part C of the survey and used infrequently by participants, future iterations of the survey should include these opportunities where appropriate, to support a thorough exploration of the subject matter. Additionally, consistent with the known strengths of qualitative research, participant responses to qualitative items provided a more comprehensive depiction of positive and negative experiences (Friborg & Rosenvinge, 2013; Yardley & Bishop, 2017). Although the qualitative items allowed participants to provide an increased level of detail in their responses, these questions were also prone to errors in interpretation with some irrelevant responses provided, in contrast to the response accuracy reported in previous comparisons of qualitative and quantitative items (e.g., Griffith et al., 1999). Overall, the response characteristics and missing topic areas suggested a slight increase in effectiveness for Part B as compared to Part C.

Relatedly, the themes emerging from the analysis of the survey feedback further supported a preference for quantitative methods, as participants identified the description of response options as helpful in guiding their responses. It is also important to note that, consistent with the known strengths of quantitative methods, exploring topics using a quantitative format supports more straightforward and measurable comparison temporally and across groups in future iterations of the survey (Yardley & Bishop, 2017). Lastly, the potential impact of sequence effects must also be considered in this comparison. Survey fatigue and the increased length of a web survey may result in increased breakoff in research focusing on post-secondary students (Hoerger, 2010; Liu & Wronski, 2017; Porter, Whitcomb, & Weitzer, 2004). In this study, only one participant who completed Part B did not complete Part C of the survey, suggesting that the compensation provided to participants was a sufficient incentive for continued participation. It is important to note that, based on the average time for survey completion, the incentive provided to participants was above the minimum wage in Ontario, but not excessively so.

Both qualitative and quantitative survey items demonstrated strengths and limitations in relation to this examination of efficiency and effectiveness. Although qualitative items were efficient in exploring the topic, there were substantial limitations in terms of effectiveness. As quantitative items were associated with lower rates of nonresponse, increased response quality, and were identified as the preferred method by the majority of participants, it is recommended that future research focusing on Autistic student experiences, and future revisions of this survey emphasize quantitative methods. However, to ensure that any experiences not presented using quantitative methods are captured, it is recommended that quantitative items include an option for participants to identify other relevant aspects not listed within the response options.

Additionally, to support increased depth and breadth of exploration, future iterations of this survey and mixed methods research focusing on the experiences of post-secondary students with ASD may benefit from the inclusion of qualitative items to support the identification of specific attributes, details, and characteristics important to student success. This is particularly relevant as the larger project aims to develop recommendations for the post-secondary setting to support the success of Autistic post-secondary students by emulating efficacious spaces, supports, and services.

The time required for participants to complete each section of the survey is also an important consideration for revision. Although participants likely completed the survey in multiple sittings, as taking breaks as needed was encouraged, and the average completion times for Parts B and C, as well as the survey overall, were well above the estimates provided by Qualtrics XM software (Qualtrics, 2020), the completion time data still provided valuable information. First, the time required to complete each part of the survey was much longer than the length of 12 minutes recommended by Qualtrics XM (n.d.) to avoid substantial break-off in web-based surveys, highlighting the importance of revision and reduction. Although the extreme scores removed through data cleaning procedures were likely representative of participants taking breaks and returning to complete the survey at a later time, the completion time reported may still be inflated. It is not surprising that the removal of these extreme scores resulted in data sets that were platykurtic, with the total time approaching excess kurtosis (DeCarlo, 1997). The skewness reported for Part A and the full survey suggested a slight excess of high scores, representative of a longer than expected duration, while the skewness reported for Parts B and C suggest a slight excess of low scores, consistent with the estimated completion time. In line with the studies conducted by Revilla (2016) and Peters and colleagues (2017), the differences in

completion time may be indicative of a higher response quality in Part C, although one also must consider the amount of time required to complete the three additional qualitative questions included in Part C.

**Survey feedback.** The feedback provided by the pilot participants highlighted several key strengths and weaknesses of the pilot survey. Although many of the themes which emerged through thematic analysis included dichotomous sentiments, some clear trends emerged. There was clear agreement amongst participants that repetitive or redundant questions should be removed and avoided as much as possible, consistent with the recommendations in the literature (Gideon, 2012). Participants were also in agreement that the option to take breaks was helpful. In identifying topic areas that were important to retain or add to the survey, participants were also generally in agreement that the survey items exploring identity were important to retain and that more exploration with consideration of experiences related to ableism and discrimination could enhance the survey, while feedback related to areas for potential adjustment was varied. Additionally, participants identified the format through which feedback was solicited as a weakness, as participants were unclear regarding expectations and instructions.

The dichotomous sentiments identified as themes through thematic analysis were often in reference to specific survey items, where some survey items were identified as strengths and others as weaknesses. For example, the sub-categories of question clarity and response options within the phrasing theme identified specific questions and response options that should be retained and others that could be improved in future iterations of the survey. The feedback related to the theme of formatting highlighted errors and omissions that could be easily corrected. However, this feedback still highlighted important considerations beyond the item-level. Specifically, although feedback identified specific items as overly long and overwhelming,

this consideration is important for the development of qualitative items in general. It is important to identify and correct problematic survey items as increased clarity regarding response length and quality expected can facilitate improved response quality in web-based surveys (Smyth et al., 2019). Some dichotomous sentiments emerged through thematic analysis where participants disagreed. For example, while some participants believed the survey to be a comprehensive exploration of important topics, others found the survey to be too long. Additionally, while some participants identified the inclusivity of exploring identity as a strength, others saw room for improvement in this area. Although all feedback will be reviewed and discussed with the steering committee before survey revisions occur, areas where dichotomous sentiments were reported will be a particular focus.

Overall, the feedback provided by pilot participants highlighted the strengths of this survey, including the exploration of important topic areas using quantitative methods, the opportunity for participants to take breaks, and the inclusion of survey items exploring individual identity. While several of the weaknesses identified were errors and omissions that were easily rectified (e.g., removing repetitive items), some areas of concern required further review. Namely, options for reducing the length of the survey while maintaining comprehensiveness and the possibility of exploring the sensitive topic of experiences related to ableism and discrimination. The perspectives shared by pilot participants highlighted the importance of continued involvement of individuals with lived experiences throughout the action inquiry process and particularly in including individuals for whom the measure being reviewed was novel.

**Strengths.** There were many strengths within the methodology and results of this study. Most importantly, this study exemplified research using a PAR approach by including



individuals with lived experiences in the review and revision of a measure developed using a PAR approach, an additional step not commonly reported or included in the existing PAR literature. The value of this involvement was further demonstrated by the compensation provided. This compensation likely facilitated increased rates of participation (Singer & Ye, 2013; Deutskens et al., 2004). This feedback provided substantial information to guide future revision of the survey. The feedback also highlighted the importance of multiple stages of review and reviewers for whom the measure is novel in the development and optimization of research measures. Additionally, this study contributed to the literature focusing on the development of mixed methods research focusing on post-secondary students with ASD, a limited area of study.

**Limitations.** Although the thematic analysis process was helpful in aggregating themes to identify general strengths and weaknesses of the survey, this process was not effective at examining item-level feedback, particularly when feedback contrasted between survey items. For instances where participant feedback related to a specific survey item, using a method of analysis separate from the process of thematic analysis would have been more effective in identifying specific items for revision. Additionally, as feedback was provided through an online survey format, researchers were not able to follow up with participants to clarify or further discuss feedback. Additional communication may have also mitigated a limitation identified by pilot participants related to the format for providing feedback. Specifically, additional review of Part D instructions over email, phone, or videoconference would have provided an opportunity for clarification. Lastly, although participants reported their gender identity, the survey did not ask participants to provide their pronouns. Although the use of the singular “they” protected the privacy of participants in this pilot group, this question should be incorporated in future

iterations of this survey to ensure that excerpts are reported in a way that is consistent with a participant's identity.

**Future directions.** The results of this study will be utilized primarily to guide the revision of the pilot survey with the steering committee in preparation for administration across Ontario. However, the findings also highlight important considerations for future research in general. Namely, this study provides a model of PAR in including individuals with lived experiences in measure testing. The input and involvement of individuals with lived experiences should be incorporated in all research and practice impacting individuals on the autism spectrum. Additionally, the results of this study suggest that individuals on the autism spectrum may prefer surveys with a quantitative emphasis, particularly when their experiences with the subject matter are limited or the question is unclear. Quantitative methods may also be more effective in exploring this subject matter, although potentially less efficient in terms of time commitment as compared to qualitative methods. The results of this comparative analysis and other findings should be explored further in future mixed methods research with a larger sample size to support the development of stronger conclusions and guide the development of future research measures.

**Conclusion.** This study was successful in gathering information regarding the strengths and limitations of this survey using a participatory approach to guide further survey revisions. In addition to providing evidence to support revision specific to this survey, this study generated findings which will be used to guide decisions related to survey development in research focusing on post-secondary students on the autism spectrum in general.

## Chapter 5: General Discussion

Overall, this thesis effectively utilized a PAR approach to develop and identify potential revisions for a survey examining the needs of post-secondary students with ASD. Based on the results described in this thesis, the survey will be revised in consultation with the steering committee to prepare for the Ontario and pan-Canadian administration.

### Discussion

The studies described in Chapters 2-4 depicted the iterative process of research using a PAR approach. Separating this research into multiple studies supported the detailed examination of the findings, strengths, and limitations of each separate step in the research process. Several trends and similarities were present and pervasive throughout the research process.

Although the planning and development process for all good research requires time and consideration, this is known to be particularly true when using a PAR approach (MacLeod, 2010). Before important discussions regarding planning and development could occur, the members of the steering committee needed to meet. As steering committee members were also balancing various employment, academic, and personal obligations, finding a time for meetings where most steering committee members could attend was challenging. Challenges related to availability were mitigated by technology, which allowed steering committee members to connect from any location. Steering committee members who could not attend meetings were able to review the minutes and materials online at their convenience, ensuring that all steering committee members were updated on recent progress and could be involved in all decisions.

Similarly, the recruitment process for the pilot testing required more time than anticipated. In addition to the time required to recruit a sufficient number of eligible and interested individuals, several participants also required additional time to complete the survey.

Anecdotally, some participants shared that academic or personal obligations delayed survey completion. Again, technology likely facilitated increased participation as participants could complete the survey in any location with a computer or smartphone and an internet connection. Although research using a PAR approach, or any research requiring collaboration may be more time-consuming, the value of the insights gained and increased credibility and relevance of the findings are essential to the development of quality research. Therefore, it is important that researchers using a PAR approach include flexibility and additional time to anticipate these potential delays, as well as leveraging technology where possible to reduce the response effort required for connection.

It is also important to acknowledge the unique circumstances under which much of this research occurred which further impacted the timeline. Specifically, the pilot survey and later meetings with the steering committee were conducted amidst the COVID-19 pandemic in Ontario in 2020. The steering committee spent time considering the potential impacts and opportunities related to conducting research during this unprecedented time and ultimately decided to proceed as planned. The additional burdens of navigating these circumstances likely further impacted recruitment as students transitioned to online learning and graduates entered the workforce. The impact of the pandemic on students is an emerging topic in research. Recent research conducted in Ontario has suggested that challenges encountered by post-secondary students with disabilities transitioning to online learning outweighed any benefits gained and contributed to substantial negative impacts on mental health (Mullins, 2020). This research focused on the results of a survey completed by 222 post-secondary students attending university in Ontario. Although this research included students who identified as Autistic, further

exploration of the impacts of this evolving situation is warranted to determine the potential outcomes for students, recent graduates, and other individuals on the autism spectrum.

The process described by McCalman and colleagues (2017) was effective in guiding the development and revision of a survey using a PAR approach. Although the research outlined in this thesis focused on the first four stages of the framework, with the first three stages depicted in the first study, and the fourth stage described in the second and third studies, this project is well-positioned to complete the final stages. The suggestions for survey revision, administration of the refined measure, and dissemination of results have provided a wealth of data to guide the steering committee in preparation for the Ontario administration. Further, this research provided evidence in support of developing and conducting research using a PAR approach.

**Strengths.** First and foremost, a strength of this research was that it expanded on previous research by meaningfully involving individuals with lived experiences in all phases, which lent credibility to the findings and facilitated an authentic depiction of experiences of Autistic post-secondary students. The results of this study were amplified by the methodology incorporating review by and feedback from individuals with ASD. This research also contributes meaningfully to the body of Canadian literature, as few studies focusing on Canadian Autistic learners have been published. The lack of research focusing on post-secondary students with ASD outside of the US and UK is an existing gap in the literature (Anderson et al., 2017). This research also expanded on the literature by including Autistic learners who had stopped attending post-secondary studies, a gap identified by Gelbar and colleagues (2015). Another strength present throughout this thesis was the use of technology to facilitate connection and reduce response effort. Virtual methods of communication and participation allowed individuals to

access materials at their convenience and mitigated the impact of challenges related to the COVID-19 pandemic.

**Limitations.** There are several opportunities for improvement which may have enhanced this research if addressed. Namely, the sample size for the pilot survey and the size of the steering committee were both smaller than ideal, despite being comparable with much of the published research (e.g., Berry, 2018; Casement et al., 2017; Cox et al., 2015; LeGary, 2017; Vincent et al., 2017). Although feedback from pilot participants helped to mitigate concerns related to sample size in survey development, it is important that the Ontario survey reach a sufficiently large and representative sample to ensure the findings are generalizable and provide appropriate statistical power to support more in-depth analyses. Additionally, a substantial limitation of this project, which has also been identified in the research literature focusing on individuals with ASD (e.g., Sarrett, 2018) was the lack of inclusion of individuals on the autism spectrum in the interpretation of the results, representative of a quintessential PAR approach (e.g., McCalman et al., 2017). This limitation will be addressed in the larger project as results and feedback from the pilot survey will be analyzed by and reviewed with the steering committee. Lastly, a possible limitation was the lack of survey materials available in French. Although only one participant identified as Franco Ontarien in the current sample, it is likely that some future participants will speak French. Therefore, it is recommended that survey materials be translated and available upon request.

**Future research.** The aim of this thesis was to develop and refine a survey using a PAR approach in preparation for an Ontario and pan-Canadian administration. The findings presented in this thesis suggest that following revision, this survey will facilitate a comprehensive examination of the strengths, experiences, and needs of Canadian Autistic post-secondary

students. This research will allow stakeholders to identify areas of need and examine patterns to develop recommendations specific to Canadian post-secondary students on the autism spectrum. These recommendations will inform the development of programs, supports, and services for Autistic post-secondary students and allow students, staff, educators, and policymakers to better address the needs of post-secondary students with ASD. The larger sample size in these future surveys will support the reporting of student needs at the school and program level, a future direction for research identified by Roux and colleagues (2015). The Ontario administration of this survey seeks to report on the largest participant group of post-secondary studies with ASD in the current literature, which will be further expanded through the pan-Canadian administration.

This thesis exemplified the opportunities associated with research using a PAR approach. In addition to identifying important topics and methodology which enhanced the survey overall, the involvement of individuals with lived experiences provided additional credibility to the findings, as well as a more authentic and relevant depiction of the experiences of Autistic post-secondary students. In future research focusing on underrepresented populations, it is recommended that individuals with lived experiences be involved in all phases of the action inquiry process.

## **Conclusion**

The quality and relevance of research is enhanced by participatory action. The benefits of systematic research using a PAR approach were central to this thesis. The research described above demonstrated that utilizing a systematic framework can effectively guide the development and administration of a high-quality research measure in research using a PAR approach. Collaboration with individuals with relevant lived experiences in addition to consultation of the literature produced a comprehensive and credible examination of the subject matter in this thesis.

The unique perspectives and insights of individuals with relationally acquired knowledge not only contributed substantially to the development of the measure through collaboration as a steering committee, but through pilot survey testing conducted with a separate group of students, graduates, and one individual who had stopped attending studies as well. In exploring the subject matter, this thesis confirmed that the strengths, experiences, and needs of Canadian Autistic post-secondary students are unique. Although there were individual differences in personal strengths and limitations, trends and themes emerged when results were analyzed collectively. As this thesis reported on phases of a larger project and produced preliminary findings, it is imperative that this research continue to support the development of recommendations and best practices for supporting the success of post-secondary students on the autism spectrum. The next steps in this project will support a fulsome examination of the strengths, experiences, and needs of Canadian Autistic post-secondary students. Future research focusing on underrepresented populations would benefit greatly from the inclusion of a PAR approach to support relevance and credibility.



## References

- Adreon, D., & Durocher, J. S. (2007). Evaluating the college transition needs of individuals with high-functioning Autism Spectrum Disorders. *Intervention on School & Clinic, 42*, 271-279.
- Alcorn MacKay, S. (2010). *Identifying Trends and Supports for Students with Autism Spectrum Disorder Transitioning into Postsecondary*. Toronto: Higher Education Quality Council of Ontario.
- American Psychiatric Association. (2018, August). *What is Autism Spectrum Disorder?*  
<https://www.psychiatry.org/patients-families/autism/what-is-autism-spectrum-disorder>
- American Psychological Association (2019, September). *Gender*. APA style.  
<https://apastyle.apa.org/style-grammar-guidelines/bias-free-language/gender>
- Ames, M.E., McMorris, C.A., Alli, L.N., & Bebko, J.M. (2016) Overview and evaluation of a mentorship program for university students with ASD. *Focus on Autism and Other Developmental Disabilities, 31*(1), 27–36.
- Anderson, A. H., Carter, M., & Stephenson, J. (2018). Perspectives of university students with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 48*(3), 651–665.
- Anderson, A. H., Stephenson, J., & Carter, M. (2017). Review: A systematic literature review of the experiences and supports of students with Autism Spectrum Disorder in post-secondary education. *Research in Autism Spectrum Disorders, 39*, 33-53.  
<https://doi.org/10.1016/j.rasd.2017.04.002>
- Anderson, A.H., Stephenson, J., Carter, M. & Carlon, S. (2019). A systematic literature review of empirical research on postsecondary students with Autism Spectrum Disorder. *Journal*

- of Autism and Developmental Disorders*, 49(4), 1531–1558.  
<https://doi.org/10.1007/s10803-018-3840-2>
- Autism Speaks (n.d.). What is Asperger syndrome? Retrieved from  
<https://www.autismspeaks.org/types-autism-what-asperger-syndrome>
- Autistics for Autistics (2019). *Reforming National Autism Policies: A Report*. Retrieved from  
<https://a4aontario.com/2019/10/15/our-report-to-the-government-of-canada-introduction/>
- Baker, R. W., & Siryk, B. (1989). Student Adaptation to College Questionnaire (SACQ). [Measurement instrument]. Los Angeles, CA: Western Psychological Services.
- Baker, R. W., & Siryk, B. (1999). *Student Adaptation to College Questionnaire (SACQ)* [Manual]. Torrance, CA: Western Psychological Services.
- Barnhill, G. P. (2016). Supporting students with Asperger Syndrome on college campuses: Current practices. *Focus on Autism and Other Developmental Disabilities*, 31(1), 3–15.  
<https://doi.org/10.1177/1088357614523121>
- Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Epidemiology and Community Health*, 60(10), 854–857.  
<https://doi.org/10.1136/jech.2004.028662>
- Bellini, S. (2016). Social skill deficits and anxiety in high-functioning adolescents With Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 19(2), 78–86. <https://doi.org/10.1177/10883576040190020201>
- Berry, K. M. (2018). *Experiences of students with Autism Spectrum Disorder in Mississippi community colleges* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses Global database. (UMI No. 10808556)

- Black, T.R., (2005) *Doing quantitative research in the social sciences: An integrated approach to research design, measurement, and statistics*. London, England: SAGE Publications Ltd.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <https://dx.doi.org/10.1191/1478088706qp063oa>
- Cameron, C., & Moore, M. (2013). Disability studies. In C. Cameron (Ed.), *Disability studies: A student's guide* (pp. 37-40). London, England: SAGE Publications Ltd.
- Casement, S., Carpio de los Pinos, C., & Forrester-Jones, R. (2017). Experiences of university life for students with Asperger's Syndrome: A comparative study between Spain and England. *International Journal of Inclusive Education*, 21(1), 73–89. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=EJ1121790&site=eds-live&scope=site>
- Centers for Disease Control and Prevention (2020, September). *Data & statistics on Autism Spectrum Disorder*. <https://www.cdc.gov/ncbddd/autism/data.html>
- Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*[electronic resource]. Retrieved from <http://search.ebscohost.com.proxy.library.brocku.ca/login.aspx?direct=true&db=cat00778a&AN=bu.b1656514&site=eds-live&scope=site>
- Chevalier, J. M., & Buckles, D. (2019). *Participatory action research: Theory and methods for engaged inquiry*. Routledge. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=cat00778a&AN=bu.b3171444&site=eds-live&scope=site>

- Council of Ontario Universities (2021, January). Diversity. Ontario's universities: Partnering for a better future. <https://ontariosuniversities.ca/issues-priorities/diversity>
- Covell, C., Sidani, S., & Ritchie, J. (2012). Does the sequence of data collection influence participants' responses to closed and open-ended questions? A methodological study. *International Journal of Nursing Studies*, 49(6), 664–671.  
<https://doi.org/10.1016/j.ijnurstu.2011.12.002>
- Cox, B. E., Thompson, K., Anderson, A., Mintz, A., Locks, T., Morgan, L., ... Wolz, A. (2017). College experiences for students with Autism Spectrum Disorder: Personal identity, public disclosure, and institutional support. *Journal of College Student Development*, 58(1), 71–87.
- Credé, M., & Niehorster, S. (2012). Adjustment to college as measured by the Student Adaptation to College Questionnaire: A quantitative review of its structure and relationships with correlates and consequences. *Educational Psychology Review*, 24(1), 133–165. <https://doi.org/10.1007/s10648-011-9184-5>
- Creswell, J., & Plano Clark, V. (2011). *Designing and conducting mixed methods research* (2<sup>nd</sup>ed.). Thousand Oaks, California: SAGE Publications.
- Cullen, J. A. (2015). The needs of college students with Autism Spectrum Disorders and Asperger's Syndrome. *Journal of Postsecondary Education and Disability*, 28(1), 89-101.
- DeCarlo, L. T. (1997). On the meaning and use of kurtosis. *Psychological Methods*, 2(3), 292-307. <https://doi.org/10.1037/1082-989X.2.3.292>
- Deutskens, E., De Ruyter, K., Wetzels, M. & Oosterveld, P. (2004). Response rate and response quality of internet-based surveys: An experimental study. *Marketing Letters*, 15(1), 21–36.

- Dewinter, J., De Graaf, H., & Begeer, S. (2017). Sexual orientation, gender identity, and romantic relationships in adolescents and adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 47*(9), 2927–2934.
- Doodle AG (2019). Doodle (Version 4.15.3) [Mobile application software]. Retrieved from <https://doodle.com/en/>
- Doron, G., Brunstein-Klomek, A., Sadeh-Sharvit, S., Milton, A., Ellis, L., Davenport, T... & Hickie, I. (2017). Comparison of self-reported telephone interviewing and web-based survey responses: Findings from the second Australian young and well national survey. *JMIR Mental Health, 4*(3), e37. <https://doi.org/10.2196/mental.8222>
- Dropbox Inc. (2020). Dropbox Desktop app (Version 107.4.4453) [Mobile application software]. Retrieved from <https://www.dropbox.com>
- Dudgeon, P., Scrine, C., Cox, A., & Walker, R. (2017). Facilitating empowerment and self-determination through participatory action research: Findings from the national empowerment project. *International Journal of Qualitative Methods, 16*(1). <https://doi.org/10.1177/1609406917699515>
- Fetters, M.D., Curry, L.A., & Creswell, J.W. (2013). Achieving integration in mixed methods designs: Principles and practices. *Health Services Research, 48*(6), 2134-2156.
- Flicker, S., Maley, O., Ridgley, A., Biscope, S., Lombardo, C., & Skinner, H. (2008). e-PAR: Using technology and participatory action research to engage youth in health promotion. *Action Research, 6*(3), 285–303. <https://doi.org/10.1177/1476750307083711>
- Friborg, O., & Rosenvinge, J.H. (2013). A comparison of open-ended and closed questions in the prediction of mental health. *Quality and Quantity, 47*, 1397-1411

- Fryrear, A. (2016, February 25). Survey tips: 5 easy ways to avoid survey fatigue in your respondents [Blog post]. Retrieved from <https://www.surveygizmo.com/resources/blog/5-easy-ways-to-avoid-survey-fatigue/>
- Fullick, M., (2015, July 5). A missed opportunity to contrast Canadian and U.S. higher-ed systems. *University Affairs*. <https://www.universityaffairs.ca/opinion/speculative-diction/a-missed-opportunity-to-contrast-canadian-and-u-s-higher-ed-systems/>
- Galesic, M. & Bosnjak, M. (2009). Effects of questionnaire length on participation and indicators of response quality in a web survey. *Public Opinion Quarterly*, 73(2), 349–360, <https://doi.org/10.1093/poq/nfp031>
- Geisen, E. & Bergstrom, J.R. (2017). *Usability testing for survey research*. Cambridge, MA: Morgan Kauffman Publishers.
- Gelbar, N. W., Shefyck, A., & Reichow, B. (2015). A comprehensive survey of current and former college students with Autism Spectrum Disorders. *The Yale Journal of Biology and Medicine*, 88(1), 45–68.
- George, S. & Stokes, M.A. (2018). Sexual orientation in Autism Spectrum Disorder. *Autism Research*, 11(1), 133–141. <https://doi.org/10.1002/aur.1892>
- Gibbs, L., Kornbluh, M., Marinkovic, K., Bell, S., & Ozer, E.J. (2020). Using technology to scale up youth-led participatory action research: A systematic review. *Journal of Adolescent Health*, 67, 14-23.
- Gideon, L. (2012). *Handbook of survey methodology for the social sciences*. New York, NY: Springer.

- Giles, D. (2014). “DSM-V is taking away our identity”: The reaction of the online community to the proposed changes in the diagnosis of Asperger’s disorder. *Health, 18*(2), 179–195.  
<https://doi.org/10.1177/1363459313488006>
- Glass, R., & Newman, A. (2015). Ethical and epistemic dilemmas in knowledge production: Addressing their intersection in collaborative, community-based research. *Theory and Research in Education, 13*(1), 23–37. <https://doi.org/10.1177/1477878515571178>
- Glassman, M., & Erdem, G. (2014). Participatory action research and its meanings: Vivencia, praxis, conscientization. *Adult Education Quarterly, 64*(3), 206–221.  
<https://doi.org/10.1177/0741713614523667>
- Glennon, T. J. (2001). The stress of the university experience for students with Asperger Syndrome. *Work, 17*, 183–190.
- Glidden, D., Bouman, W. P., Jones, B. A., & Arcelus, J. (2016). Gender dysphoria and Autism Spectrum Disorder: A systematic review of the literature. *Sexual Medicine Reviews, 4*(1), 3–14.
- Google LLC (2020). Google Docs (Version 1.20.122.03.40) [Mobile application software]. Retrieved from <https://www.google.ca/docs>
- Göriz, A. S. (2006). Incentives in web studies: Methodological issues and a review. *International Journal of Internet Science, 1*(1), 58–70.
- Griffith, L. E., Cook, D. J., Guyatt, G. H., & Charles, C. A. (1999). Comparison of open and closed questionnaire formats in obtaining demographic information from Canadian general internists. *Journal of Clinical Epidemiology, 52*(10), 997–1005.
- Gurbuz, E., Hanley, M., & Riby, D. M. (2019). University students with Autism: The social and academic experiences of university in the UK. *Journal of Autism and Developmental*

- Disorders*, 49(2), 617-631. <https://doi-org.proxy.library.brocku.ca/10.1007/s10803-018-3741-4>
- Heath, J. (2015, June 8). Why Canadian professors aren't afraid of their students. *Ottawa Citizen*. <https://ottawacitizen.com/opinion/columnists/heath-why-canadian-professors-arent-afraid-of-their-students>
- Hendrickson, J. M., Carson, R., Woods-Groves, S., Mendenhall, J., & Scheidecker, B. (2013). UI REACH: A postsecondary program serving students with Autism and intellectual disabilities. *Education and Treatment of Children*, 36(4), 169–194.
- Hoerger, M. (2010). Participant dropout as a function of survey length in internet-mediated university studies: Implications for study design and voluntary participation in psychological research. *Cyberpsychology, Behavior and Social Networking*, 13(6), 697–700. <https://doi.org/10.1089/cyber.2009.0445>
- Hofvander, B., Delorme, R., Chaste, P., Nydén, A., Wentz, E., Ståhlberg, O., ... Leboyer, M. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*, 9(1), 35–35. <https://doi.org/10.1186/1471-244x-9-35>
- Hotez, E., Shane-Simpson, C., Obeid, R. DeNigris, D.; Siller, M., Costikas, C. ... Gillespie-Lynch, K. (2018). Designing a summer transition program for incoming and current college students on the autism spectrum: A participatory approach. *Frontiers in Psychology*, 9(46), 1-16
- IBM Corp. (2019). IBM SPSS Statistics for Windows (Version 26.0) [Mobile application software]. Armonk, NY: IBM Corp.



- Ivis, F. J., Bondy, S. J., & Adlaf, E. M. (1997). The effect of question structure on self-reports of heavy drinking: Closed-ended versus open-ended questions. *Journal of Studies on Alcohol*, 58(6), 622–624.
- Jackson, S. L. J., Hart, L., Brown, J. T., & Volkmar, F. R. (2018). Brief report: self-reported academic, social, and mental health experiences of post-secondary students with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 48(3), 643–650.  
<https://doi-org.proxy.library.brocku.ca/10.1007/s10803-017-3315-x>
- Jex, S., Adams, G., Elacqua, T., & Lux, D. (1997). A comparison of incident-based and scale measures of work stressors. *Work & Stress*, 11(3), 229–238.
- Jick, T.D., (1979). Mixing qualitative and quantitative methods: Triangulation in action. *Administrative Science Quarterly*, 24, 602-611.
- Johnson Hess, A. (2018, May 14). Why students are choosing to go to college in Canada instead of the United States. *CNBC*. <https://www.cnn.com/2017/08/09/why-students-are-choosing-to-go-to-college-in-canada-instead-of-the-us.html>
- Kelley, K., Clark, B., Brown, V., & Sitzia, J. (2003). Good practice in the conduct and reporting of survey research. *International Journal for Quality in Health Care*, 15(3), 261–266.  
<https://doi-org.proxy.library.brocku.ca/intqhc/mzg031>
- Kindon, S., Pain, R., & Kesby, M. (2007). *Participatory action research approaches and methods connecting people, participation and place*. Routledge, Taylor & Francis Group.  
Retrieved from <https://ebookcentral-proquest.com.proxy.library.brocku.ca/lib/brocku/reader.action?docID=325513>
- Klassen, A., Creswell, J., Plano Clark, V., Smith, K., & Meissner, H. (2012). Best practices in mixed methods for quality of life research. *Quality of Life Research*, 21(3), 377–380.

- Knott, F., & Taylor, A. (2014). Life at university with Asperger Syndrome: A comparison of student and staff perspectives. *International Journal of Inclusive Education*, 18, 411 - 426.
- Koegel, L. K., Ashbaugh, K., Koegel, R. L., Detar, W. J., & Regester, A. (2013). Increasing socialization in adults with Asperger's syndrome. *Psychology in the Schools*, 50(9), 899-909. <https://doi.org/10.1002/pits.21715>
- Krajniak, M., Pievsky, M., Eisen, A., & McGrath, R. (2018). The relationship between personality disorder traits, emotional intelligence, and college adjustment. *Journal of Clinical Psychology*, 74(7), 1160–1173. <https://doi.org/10.1002/jclp.22572>
- Lefever, S., Dal, M., & Matthiasdottir, A. (2007). Online data collection in academic research: Advantages and limitations. *British Journal of Educational Technology*, 38(4), 574–582.
- LeGary, R. A., (2017). College students with Autism Spectrum Disorder: Perceptions of social supports that buffer college-related stress and facilitate academic success. *Journal of Postsecondary Education and Disability*, 30(3), 251–268.
- Lifesize Inc. (2020). Lifesize Cloud Video Conferencing (Version 2.2.92-52068) [Mobile application software]. Retrieved from <https://webapp.lifesizecloud.com/>
- Linton, K., Kreck, T., Sensui, L., Spillers, J., & Lacasse, J. (2014). Opinions of people who self-identify with Autism and Asperger's on DSM-5 criteria. *Research on Social Work Practice*, 24(1), 67–77. <https://doi.org/10.1177/1049731513495457>
- Liu, M., & Wronski, L. (2018). Examining completion rates in web surveys via over 25,000 real-world surveys. *Social Science Computer Review*, 36(1), 116–124.
- Liveboard LLC (2017). LiveBoard Interactive Whiteboard (Version 4.8.1) [Mobile application software]. Retrieved from <https://liveboard.online/>

- Louie, B. (2016). *Healthy participation: Youth-led participatory action research and community health promotion in West Sacramento* (Master's thesis). Retrieved from ProQuest Dissertations and Theses Global database. (UMI No. 10182816)
- Lovibond, S. H., & Lovibond, P. F. (1995). 21-Item Depression Anxiety and Stress Scale(DASS-21) [Measurement instrument]. Sydney, AU: The Psychology Foundation of Australia Inc.
- Luey, J. (2014). Participating, navigating and succeeding with Autism Spectrum Disorder in the Ontario postsecondary education system. *College Quarterly*, 17(4), 1-15.
- Madriaga, M. (2010). 'I avoid pubs and the student union like the plague': Students with Asperger Syndrome and their negotiation of university spaces. *Children's Geographies*, 8(1), 23-34.
- Malterud, K. (2001). Qualitative research: Standards, challenges, and guidelines. *Lancet*, 358, 483-488. [https://doi-org.proxy.library.brocku.ca/10.1016/S0140-6736\(01\)05627-6](https://doi-org.proxy.library.brocku.ca/10.1016/S0140-6736(01)05627-6)
- MacLeod, A. (2010). Welcome to my first rant!: Report on a participatory pilot project to develop the 'AS portal', an online peer support network for higher education students on the autism spectrum. *Journal of Assistive Technologies*, 4(1), 14-24.
- MacLeod, A., & Green, S. (2009). Beyond the books: Case study of a collaborative and holistic support model for university students with Asperger Syndrome. *Studies in Higher Education*, 34, 631-646.
- Maxam, S.L. (2012). *Creating an inclusive collegiate learning environment for students on the autism spectrum: A participatory action research study* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses Global database. (UMI No. 3535981)

- Mayes, S.D. & Calhoun, S.L. (2006) Frequency of reading, math, and writing disabilities in children with clinical disorders. *Learning and Individual Differences* 16(2), 145—57.
- Mazzola, J., Walker, E., Shockley, K., & Spector, P. (2011). Examining stress in graduate assistants: Combining qualitative and quantitative survey methods. *Journal of Mixed Methods Research*, 5(3), 198–211. <https://doi.org/10.1177/1558689811402086>
- McAndrew, L., Slotkin, S., Kimber, J., Maestro, K., Phillips, L., Martin, J., ... Eklund, A. (2019). Cultural incongruity predicts adjustment to college for student veterans. *Journal of Counseling Psychology*, 66(6), 678–689. <https://doi.org/10.1037/cou0000363>
- McCalman, J., Bainbridge, R. G., Redman-Maclaren, M., Russo, S., Rutherford, K., Tsey, K., Ungar, M., Wenitong, M., & Hunter, E. (2017) The development of a survey instrument to assess Aboriginal and Torres Strait Islander students’ resilience and risk. *Frontiers in Education*, 2(19), 1-13.
- McLeod, J. D., Meanwell, E., & Hawbaker, A. (2019). The experiences of college students on the Autism Spectrum: A comparison to their neurotypical peers. *Journal of Autism and Developmental Disorders*, 49(6), 2320–2336. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=EJ1217799&site=eds-live&scope=site>
- McMorris, C.A., Baraskewich, J., Ames, M.A., Shaikh, K.T., Ncube, B.L., & Bebko, J.M. (2019). Mental health issues in post-secondary students with Autism Spectrum Disorder: Experiences in accessing services. *International Journal of Mental Health and Addiction*, 17(3), 585–595. <https://doi.org/10.1007/s11469-018-9988-3>
- Microsoft Corporation (2020). Microsoft Excel for Microsoft Office 365 MSO (Version 2008) [Mobile application software]. Redmond, WA: Microsoft Corporation

- Microsoft Corporation (2020). Microsoft Word for Microsoft Office 365 MSO (Version 2008) [Mobile application software]. Redmond, WA: Microsoft Corporation
- Morrison, J., Sansosti, F., & Hadley, W. (2009). Parent perceptions of the anticipated needs and expectations for support for their college-bound students with Asperger's Syndrome. *Journal of Postsecondary Education and Disability, 22*(2), 78-87.
- Morse, M. (1991). Approaches to qualitative-quantitative methodological triangulation. *Nursing Research, 40*(2), 120–123. <https://doi.org/10.1097/00006199-199103000-00014>
- Mullins, L. (2020). *The Transition Online: The Impact of COVID-19 on Students with Disabilities in Higher Education*. St. Catharines, ON: Brock University.
- Ncube, B.L., Shaikh, K.T., Ames, M.E., McMorris, C.A., & Bebko, J.M. (2019). Social support in postsecondary students with Autism Spectrum Disorder. *International Journal of Mental Health and Addiction, 17*, 573-584.
- Ness, B. M. (2013). Supporting self-regulated learning for college students with Asperger Syndrome: Exploring the "Strategies for College Learning" model. *Mentoring & Tutoring: Partnership in Learning, 21*, 356-377.
- Newport, C. (2016). *Deep work: Rules for focused success in a distracted world*. Grand Central Publishing.
- Onwuegbuzie, A. J., & Collins, K. M. (2007). A typology of mixed methods sampling designs in social science research. *The Qualitative Report, 12*(2), 281-316.
- Ostlund, U., Kidd, L., Wengstrom, Y., & Rowa-Dewar, N., (2011). Combining qualitative and quantitative research within mixed method research designs: A methodological review. *International Journal of Nursing Studies, 48*, 369 – 383.

- Peters, J., Hall, C. and Skinkle, R. (2017) *The Impact of Incentives, Communications and Task Demand on Postsecondary Student Participation in Online Research*. Toronto, ON: Higher Education Quality Council of Ontario.
- Porter, S.R., Whitcomb, M.E., & Weitzer, M.H., (2004). Multiple surveys of students and survey fatigue. *New Directions for Institutional Research*, 2004(121), 63–73.  
<https://doi.org/10.1002/ir.101>
- Public Health Agency of Canada (2018, March). *Autism Spectrum Disorder among children and youth in Canada 2018: A report of the national Autism Spectrum Disorder surveillance system*. Ottawa, ON: Government of Canada
- Qualtrics (2020). Qualtrics XM [Mobile application software]. Retrieved from <https://www.qualtrics.com>
- Qualtrics XM (n.d.). Survey methodology & compliance best practices [Blog post]. Retrieved from <https://www.qualtrics.com/support/survey-platform/survey-module/survey-checker/survey-methodology-compliance-best-practices/>
- Qualtrics XM (2020.). User testing 101: The complete guide in 2020 [Blog post]. Retrieved from <https://www.qualtrics.com/experience-management/customer/user-testing-guide/>
- Quinn, S., Gleeson, C. I., & Nolan, C. (2013). An occupational therapy support service for university students with Asperger’s Syndrome (AS). *Occupational Therapy in Mental Health*, 29(1), 109–125.
- Ramler, T., Tennison, L., Lynch, J., & Murphy, P. (2015). Mindfulness and the college transition: The efficacy of an adapted mindfulness-based stress reduction intervention in fostering adjustment among first-year students. *Mindfulness*, 7(1), 179–188.

- Revilla, M. (2016). Impact of raising awareness of respondents on the measurement quality in a web survey. *Quality & Quantity*, 50(4), 1469–1486.
- Roberts, N. & Birmingham, E. (2017) Mentoring university students with ASD: A mentee-centered approach. *Journal of Autism and Developmental Disorders*, 47, 1038-1050.
- Robson, L., Anisef, P., Brown, R., Nagoaka, J. (2019) A comparison of factors determining the transition to postsecondary education in Toronto and Chicago. *Research in Comparative and International Education*, 14(3), 338-356.
- Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., and Anderson, K.A. (2015). *National Autism Indicators Report: Transition into Young Adulthood*. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.
- Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., Edwards, A. D., Wei, X., ... Yu, J. W. (2015). Characteristics of two-year college students on the autism spectrum and their support services experiences. *Autism Research and Treatment*, 2015, 1-10.
- Sarrett, J. C. (2018). Autism and accommodations in higher education: Insights from the Autism community. *Journal of Autism and Developmental Disorders*, 48(3), 679–693.
- Schindler, V., Cajiga, A., Aaronson, R., & Salas, L. (2015). The experience of transition to college for students diagnosed with Asperger's disorder. *Open Journal of Occupational Therapy*, 3(1). <https://doi.org/10.15453/2168-6408.1129>
- Schoonenboom, J., & Johnson, R. B. (2017). How to construct a mixed methods research design. *Koelner Zeitschrift Fur Soziologie Und Sozialpsychologie*, 69(2), 107-131. <https://doi-org.proxy.library.brocku.ca/10.1007/s11577-017-0454-1>
- Sendall, M., McCosker, L., Brodie, A., Hill, M., & Crane, P. (2018). Participatory action research, mixed methods, and research teams: Learning from philosophically juxtaposed

- methodologies for optimal research outcomes. *BMC Medical Research Methodology*, 18(1), 167–172.
- Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an Autism Spectrum Disorder. *Pediatrics*, 129(6), 1042–1049. <https://doi.org/10.1542/peds.2011-2864>
- Shmulsky, S., Gobbo, K., & Donahue, A. (2015). Groundwork for success: A college transition program for students with ASD. *Journal of Postsecondary Education and Disability*, 28(2), 235-241.
- Simmons, E. & Wilmot, A. (2004). Incentive payments on social surveys: A literature review. *Social Survey Methodology Bulletin*, 53, 1–11.
- Singer, E., & Ye, C. (2013). The use and effects of incentives in surveys. *The ANNALS of the American Academy of Political and Social Science*, 645(1), 112–141. <https://doi.org/10.1177/0002716212458082>
- Smith, C. P. (2007). Support services for students with Asperger's Syndrome in higher education. *College Student Journal*, 41, 515 - 531.
- Smith, J., & Noble, H. (2014). Bias in research. *Evidence Based Nursing*, 17(4), 100–101. <https://doi.org/10.1136/eb-2014-101946>
- Smyth, J., Dillman, D., Christian, L., & McBride, M. (2009). Open-ended questions in web surveys. *Public Opinion Quarterly*, 73(2), 325–337. <https://doi.org/10.1093/poq/nfp029>
- Tashakkori, A., & Teddlie, C. (2016). *SAGE handbook of mixed methods in social & behavioral research* (2<sup>nd</sup> ed.). Thousand Oaks, California: SAGE Publications.



- Taylor, M.J. (2005). Teaching students with Autistic spectrum disorders in HE. *Education and Training, 47*, 484-495.
- Trevisan, D., & Birmingham, E. (2016). Examining the relationship between autistic traits and college adjustment. *Autism, 20*(6), 719–729. <https://doi.org/10.1177/1362361315604530>
- Universities Canada (2019, December). Recent data on equity, diversity and inclusion at Canadian universities. [https://www.univcan.ca/wp-content/uploads/2020/02/UC\\_2019\\_EDI-Stats\\_EN.pdf](https://www.univcan.ca/wp-content/uploads/2020/02/UC_2019_EDI-Stats_EN.pdf)
- Usher, A., (2019). *The State of Postsecondary Education in Canada, 2019*. Toronto, ON: Higher Education Strategy Associates.
- van der Miesen, A., de Vries, A., Steensma, T. D., & Hartman, C. A. (2018). Autistic symptoms in children and adolescents with gender dysphoria. *Journal of Autism and Developmental Disorders, 48*(5), 1537–1548.
- Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with Autism Spectrum Disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders, 45*(6), 1673–1688.
- Vincent, J., Potts, M., Fletcher, D., Hodges, S., Howells, J., Mitchell, A., Mallon, B. & Ledger, T. (2017). "I think autism is like running on Windows while everyone else is a Mac": Using a participatory action research approach with students on the Autistic spectrum to rearticulate autism and the lived experience of university. *Educational Action Research, 25*(2), 300-315.
- Wallerstein, N. & Bernstein, E. (1994). Introduction to community empowerment, participatory education, and health. *Health Education Quarterly, 21*(2), 141–148. <https://doi.org/10.1177/109019819402100202>

- Walton, T. (2016). Using a mixed methods approach to investigate university student success after support service interaction: A case study and analysis. *Journal of the Australian and New Zealand Student Services Association, 48*, 38-46
- Wei, X., Christiano, E. R., Yu, J. W., Blackorby, J., Shattuck, P., & Newman, L. A. (2013). Science, technology, engineering, and mathematics (STEM) participation among college students with an Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 43*(7), 1539–1546.
- Weiss, A. L., & Rohland, P. (2015). Implementing a communication coaching program for students with Autism Spectrum Disorders in postsecondary education. *Topics in Language Disorders, 35*, 345-361.
- Western Michigan University (2020). Skills employers want in college graduates. Retrieved from <https://wmich.edu/career/students/transferableskills>
- White, S. W., Elias, R., Salinas, C. E., Capriola, N., Conner, C. M., Asselin, S. B., & ... Getzel, E. E. (2016). Students with autism spectrum disorder in college: Results from a preliminary mixed methods needs analysis. *Research in Developmental Disabilities, 56*, 29-40. <https://doi.org/10.1016/j.ridd.2016.05.010>
- White, S.W., Ollendick, T.H., & Bray, B.C. (2011). College students on the autism spectrum: Prevalence and associated problems. *Autism, 15*(6), 683–701. <https://doi.org/10.1177/1362361310393363>
- White, S. W., Richey, J.A., Gracinin, D., Coffman, M. Elias, R., LaConte, S., & Ollendick, T.H.(2016). Psychosocial and computer-assisted intervention for college students with Autism Spectrum Disorder: Preliminary support for feasibility. *Education and Training in Autism and Developmental Disabilities, 51*(3), 307–317

Wise, K. L. (2015). *A formative program evaluation of a postsecondary support program for students with high functioning autism spectrum disorder* (Doctoral dissertation).

Retrieved from Iowa Research Online, The University of Iowa's Institutional Repository.

Yardley, L. & Bishop, F.L. (2017) Mixing qualitative and quantitative methods: A pragmatic approach. In C. Willig & W. Stainton Rogers (Eds.), *The SAGE handbook of qualitative*

Appendix A  
Pilot Study Letter of Invitation



Applied Disability Studies

Strengths, Experiences, and Needs of Canadian Autistic Post-Secondary Students (SEN-CAPS): A Participatory Action Research Study

PRINCIPAL INVESTIGATOR

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We invite you to participate in the first phase of a research project called Strengths, Experiences, and Needs of Canadian Autistic Post-Secondary Students (SEN-CAPS): A Participatory Action Research Study. The SEN-CAPS project steering committee includes individuals with lived experiences relating to this topic including those who identify as having an autism spectrum disorder, family members, college/university support services staff, university faculty and students, community clinicians, and advocates. The members of this committee have actively collaborated on the content, design, testing, and implementation plan for the survey.

The purpose of this phase of the study is to test and conduct a pilot of a survey that has been developed to learn more about the strengths, experiences, and needs of autistic college and university students in Canada from the perspective of students with ASD. Participation in this research will involve approximately 3-4 hours of your time spent in completion of an online survey and providing feedback on the survey itself. This survey is divided into four sections that can be completed over the course of a week or so. If you need any accommodations or supports to complete the survey please let the researchers know, and we will do our very best to provide what you need.

As a participant, you will be asked to complete a web-based survey by answering questions about your experiences at college and/or university. After you have completed the survey, you will be asked to provide specific feedback on the relevance, fit, and clarity of questions and the

design of the survey in general. Your survey responses will be combined with the responses of other participants to provide some preliminary insights into the strengths, experiences, and needs of post-secondary students with ASD in Ontario. Your feedback on the survey will be used to improve the survey in preparation for administration of the survey in Ontario, then across Canada. You may also choose to receive more information about participating in the project in the future.

There are both direct and indirect benefits to completing this study. As a participant, you can earn up to \$100.00 for participating in this survey. Participants in this phase of the study will be compensated \$25.00 for each section of the survey (maximum 4) that they participate in. Your participation will benefit the project by helping us to create a survey that will ask meaningful questions to document the strengths, experiences, and needs of Canadian post-secondary Autistic students.

If you have never participated in research before or if you are unsure about participating, please speak to a trusted person (e.g., friend, family member, advisor, etc.) to help you decide. If you would like to participate in the survey, have questions about being a research participant, or would like more information about the study, please email [rcondillac@brocku.ca](mailto:rcondillac@brocku.ca) or [kyoung3@brocku.ca](mailto:kyoung3@brocku.ca).

If you have any questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905.688.5550 x 3035, [reb@brocku.ca](mailto:reb@brocku.ca))

Thank you,

Dr. Rosemary Condillac, C.Psych., BCBA-D  
Associate Professor  
Department of Applied Disability Studies  
Brock University

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This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board [file # 19-264 - CONDILLAC]

## Appendix B

## List of Survey Questions Included in Qualitative Thematic Analysis of Participant Strengths and Limitations, as well as Participant Recommendations for the Post-Secondary Environment

- “Transitions, such as starting at a new school or moving to a new city can be challenging, as well as exciting. Tell us what went well during your transition to [college/university] an about any struggles, challenges, or barriers that you experienced.”
- “School can be rewarding and enjoyable at times. Please describe your personal strengths and academic strengths that have helped you on your path to success at school.”
- “School can also be challenging and difficult at times. Sometimes those challenges reflect a student’s limitations, while other times they reflect obstacles or barriers within the school environment. Please describe any personal limitations and academic limitations that may have impacted your success at school.”
- “Please describe any obstacles or barriers within the school environment that may have created challenges that impacted on your success at school.”
- “We want to learn more about ways that might make [college/university] better overall for [a person on the autism spectrum]. What changes would you like to see or what would have been helpful for you on your campus? This could include suggestions about campus spaces, services, and/or course work.”











	More than weekly	-	-	-	-	-	-	-	-	-
Mental Health Services	Once	1 (8.33%)	-	-	1 (8.33%)	-	-	-	1 (8.33%)	-
	Once per term	2 (16.67%)	-	1 (8.33%)	1 (8.33%)	-	1 (8.33%)	-	1 (8.33%)	-
	Monthly	1 (8.33%)	-	1 (8.33%)	-	-	-	1 (8.33%)	-	-
	Weekly	1 (8.33%)	-	1 (8.33%)	-	-	-	1 (8.33%)	-	-
	More than weekly	-	-	-	-	-	-	-	-	-
Campus Meal Plan	Once	-	-	-	-	-	-	-	-	-
	Once per term	-	-	-	-	-	-	-	-	-
	Monthly	-	-	-	-	-	-	-	-	-
	Weekly	-	-	-	-	-	-	-	-	-
Tutoring	More than weekly	1 (8.33%)	1 (8.33%)	-	-	-	1 (8.33%)	-	-	-
	Once	-	-	-	-	-	-	-	-	-
	Once per term	-	-	-	-	-	-	-	-	-
	Monthly	1 (8.33%)	-	1 (8.33%)	-	-	1 (8.33%)	-	-	-
	Weekly	1 (8.33%)	1 (8.33%)	-	-	-	1 (8.33%)	-	-	-
	More than weekly	1 (8.33%)	-	1 (8.33%)	-	-	1 (8.33%)	-	-	-

Appendix D

Cross-Tabulation of Frequency of Access, Needs Met, and Satisfaction with Off-Campus

Services Accessed

Service	Accessed	Total	Needs Met				Satisfaction			
			Needs met	Needs mostly met	Needs some met	Needs not met	Very satisfied	Some what satisfied	Some what dissatisfied	Very dissatisfied
Autism-Specific Services	Once	1 (8.33%)	-	1 (8.33%)	-	-	-	1 (8.33%)	-	-
	Once per term	-	-	-	-	-	-	-	-	-
	Monthly	-	-	-	-	-	-	-	-	-
	Weekly	4 (33.33%)	3 (25.00%)	1 (8.33%)	-	-	4 (33.33%)	-	-	-
	More than weekly	-	-	-	-	-	-	-	-	-
Physical Health Services	Once	-	-	-	-	-	-	-	-	-
	Once per term	-	-	-	-	-	-	-	-	-
	Monthly	1 (8.33%)	1 (8.33%)	-	-	-	1 (8.33%)	-	-	-
	Weekly	1 (8.33%)	1 (8.33%)	-	-	-	1 (8.33%)	-	-	-
	More than weekly	-	-	-	-	-	-	-	-	-
Mental Health Services	Once	-	-	-	-	-	-	-	-	-
	Once per term	1 (16.67%)	1 (8.33%)	-	-	1 (8.33%)	-	1 (8.33%)	1 (8.33%)	-
	Monthly	1 (8.33%)	1 (8.33%)	-	-	-	1 (8.33%)	-	-	-
	Weekly	1 (8.33%)	-	1 (8.33%)	-	-	-	1 (8.33%)	-	-

	More than weekly	-	-	-	-	-	-	-	-	-
Meal Delivery Services	Once	-	-	-	-	-	-	-	-	-
	Once per term	-	-	-	-	-	-	-	-	-
	Monthly	1 (8.33 %)	1 (8.33 %)	-	-	-	1 (8.33 %)	-	-	-
	Weekly	-	-	-	-	-	-	-	-	-
Tutoring	More than weekly	-	-	-	-	-	-	-	-	-
	Once	-	-	-	-	-	-	-	-	-
	Once per term	-	-	-	-	-	-	-	-	-
	Monthly	-	-	-	-	-	-	-	-	-
	Weekly	1 (8.33 %)	1 (8.33 %)	-	-	-	1 (8.33 %)	-	-	-
	More than weekly	1 (8.33 %)	-	1 (8.33 %)	-	-	1 (8.33 %)	-	-	-

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## Appendix E Survey Summary Guide

Thank you for your participation in the SEN-CAPS Pilot Survey so far. The next and final part of the survey, Part D, allows you to provide feedback on the first three parts. Please don't answer the survey questions again. We want to know what you think about the questions and if you have any advice on how to make them clearer or if you think that we have missed any important questions or if you think any questions are unnecessary. Also please tell us if any questions made you uncomfortable. We will use this information to improve the survey before we open it up to students across Ontario and then across Canada.

Before you get started, we want to explain how this part of the survey works. First you will see the questions from Part A. There is a text box after each question where you can share any concerns or suggestions you have. You don't have to write in every box. Only fill out the boxes for questions you want to give feedback on. Next, you will see the questions from Part B, and will be asked to do the same thing. Finally, you will see Part C, which will also have text boxes after each question for you to provide any feedback. At the end of this survey, there is an opportunity for you to provide feedback on the survey overall and to share your ideas on how to recruit other students to participate. After the first page, you can use the table of contents in the top left corner of the page to pick the sections and questions you would like to provide feedback on. You can find a summary of each part and section of the survey below.

Part A included questions on the following topics:

- Screening questions will be used to determine if participants qualify to take the survey.
- Section one asked about you and your experiences in high school.
- Section two focused on your post-secondary program.
- Section three explored your experiences at college or university in general.
- Section four asked about experiential learning opportunities like internships, apprenticeships, and placements.
- Section five focused on work experience.
- Section six asked about other colleges and/or universities that were attended.

Part B and Part C asked questions about the topics below. Part B allowed you to describe your experiences in your own words, and Part C asked you to rate your experiences. We did this on purpose to get your feedback on which types of questions you preferred and to see how different the information was when asked in two different ways.

Both Part B and Part C asked about the following topics:

- Section one explored your experiences with spaces on campus.
- Section two asked about the supports and services on and off campus.

- Section three focused on experiences with academic accommodations.

In addition, Part C also included a fourth section that asked about your overall experiences at college or university.

After the questions about Part A, Part B, and Part C, there are a few questions about your experience taking the surveys and about any ideas you might have on how or where to recruit college and university students who identify with ASD or consider themselves Autistic.