Transportation Experiences of Autistic Young Adults: A Scoping Review and Proposal for Future Research

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Abstract

Background: Many news articles, online posts, and studies related to work and school highlight barriers to community mobility for Autistic individuals. This scoping review aimed to gain a comprehensive understanding of these challenges.

Methods: The search, conducted between January 2012 and January 2022, across platforms such as MEDLINE, Wiley, Taylor & Francis, Sage, and Google Scholar, yielded 15 relevant articles after eliminating duplicates and irrelevant studies. Articles fell into two main categories: those focusing on experiences and those examining interventions.

Results: Results indicate a scarcity of research directly investigating the mobility experiences of Autistic individuals, with the majority centered on driving difficulties among Autistic adults. Moreover, only a small number of articles explored public transit or alternative transportation methods, despite many Autistic individuals primarily relying on these modes. The interventions explored varied widely, including traffic training, transit apps, monitoring tools, specialized teaching, virtual reality, and autonomous vehicles.

Conclusion: Overall, there is emerging literature that underscores the challenges faced by Autistic individuals in driving and using public transit. However, due to limited qualitative and quantitative data, the mobility needs of Autistic individuals remain unclear. Additionally, it seems that most research originates from the United States and Australia, leaving a significant gap in understanding the Canadian context. Consequently, further investigation is warranted, particularly with the development of the National Autism Strategy. As such, the writer proposes a two-part qualitative study on the public transportation experiences of Autistic young adults.

Acknowledgements

I extend my deepest gratitude to all who contributed to the completion of this major research project (MRP). Their unwavering support, guidance, and encouragement have been indispensable on this journey.

I am especially grateful to the individuals who participated in the study, generously offering their trust, time, and expertise. My heartfelt thanks go to our industry partners for their support, enthusiasm, and collaboration. Special recognition is due to my supervisors, Dr. Michelle Wyndham-West and Dr. Ignacio Tiznado-Aitken, along with advisors Dr. Jonathan Lai, Logan Wong, and Ingrid Osswald, as well as my dear friends and research colleagues, Tamara Crasto and Parth Shah. Your patience and guidance have been instrumental in bringing this project to fruition.

In addition to those who supported me academically, I am grateful for the presence of remarkable mentors such as Melanie Bergthorson and Bob Simpson, whose wisdom and encouragement have shaped my academic journey. I would like to extend my thanks to my colleagues and friends for their unwavering support and camaraderie.

Lastly, I would like to extend my heartfelt appreciation to my family, whose unwavering support and encouragement have been the bedrock of all my accomplishments. I am forever grateful for their hard work and sacrifices which paved the way for my education. With special appreciation for my mother to whom I owe an immeasurable debt. Through her tenacity and unwavering spirit, she has proven to me that so much can be achieved with determination, resilience, and a clear vision. Moreover, she has shown me the importance and power of standing up for and with others.

Dedications:

To my sibling, whose presence forever changed the trajectory of our lives, imparting invaluable lessons and igniting within me a sense of justice that propels me much of what I do. Each day you bring more richness to our lives and this MRP stands as a testament to the profound impact of your influence. With profound gratitude and endless love, I want you to know that this accomplishment is just as much yours as mine.

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Language Use

I would like to acknowledge the importance of language when discussing individuals within the Autism community. Language serves as a powerful tool in shaping perceptions, attitudes, and the overall treatment of individuals. Since it can lead to real harm, it is crucial to recognize that the language we use can either empower or marginalize individuals, particularly those who are part of marginalized communities.

In the Autism community, there is a range of perspectives on preferred labels (Botha et al., 2023; Zajic & Gudknecht, 2024). As such, there is no one way to refer to members of the Autism community. While some individuals may advocate for person-first language (individuals with autism) to emphasize their humanity, others advocate for identity-first language (Autistic individuals) to affirm their autism as an integral aspect of their identity. This variance in preference stems from deeply personal experiences and the multifaceted nature of the autism spectrum.

In this paper, I have made a deliberate choice to utilize identity-first language. This decision was made to reflect the importance of the Autism experience and the increased support for identity first language seen in the literature.

Positionality Statement

I first became interested in the intersection between public transportation and Autistic individuals on a personal level. Watching my younger sibling, who is on the spectrum, learn to ride the bus to school, I understood that our transit, like many systems, was not designed with their needs in mind. As such, for a long time my sibling struggled with using the bus, train and metro systems in our home, Montreal. They routinely mentioned that taking it would make them anxious and would find any reason to avoid taking it.

Over the years, we have tried to support them by taking the bus and metro together and providing them with other supports (e.g., noise cancelling headphones). However, this was not enough. They were still uncomfortable taking public transportation, especially with new routes. It would only be years later that they would be comfortable taking the bus to weekend activities with friends.

I realized that my sibling was not alone in their experience. As an occupational therapist, working primarily with Neurodiverse youth and children, I have heard many of my clients express difficulty and concern when taking the bus, train, and metro, making it difficult get to and from appointments and activities.

When I went back to school to study inclusive design, I learnt that there was almost no research on this overlap. Disappointed by the lack of knowledge and motivated by the recent changes in Canadian legislation on accessibility and Autism, this became the focus of my MRP. I hope this project will begin to address this gap and that together we can make some much-needed improvements to make public transportation more accessible and pleasant for all riders.

As a sibling and a healthcare provider, I bring my own perspective and passion to this work. I recognize that these experiences provide me with a specific view on the topic and that they have influenced the way I go about this work. Indeed, I am aware of how personal experiences might influence the research process and interpretation of findings. By examining my perspectives, I hope to limit the negative impact of my own biases. I know that I have a gap in what I know, and I aim to approach this research with an open mind while valuing the different perspectives of my participants.

I believe that while numerical data is important, qualitative research reveals context and information that quantitative measures may overlook. My research is influenced by principles of inclusive design and both participatory and emancipatory research models, as I value collaborative engagement with participants as active co-creators of knowledge.

My work encompasses various models of disability and perception, each contributing to a multifaceted understanding of human experience. Drawing from the Neuro-affirming/Neurodiversity model, I acknowledge the profound influence of neurological differences on individual perspectives. Additionally, I integrate the Bio-psycho-social model of disability, recognizing the intricate interplay among biological, psychological, and social factors in shaping one's lived experience. Lastly, my exploration is informed by lenses of queer and intersectional feminist theories, illuminating the complex intersections of identity and their profound impact on the human condition. Together, these elements converge to shape my perspective, guiding me towards fostering a holistic, equitable, and empathetic approach to research and design.

I am grateful for having the privilege to work with many incredible opportunities and thankful to you, the reader, for taking the time to read my work.

Liam Bienstock

Part 1: Scoping Review Regarding Mobility Experiences of Autistic Adults

Introduction

Role of Transportation

For all people, accessing work, leisure, and educational activities is critical for achieving financial and social independence, which is critical for a decent quality of life. Indeed, access to transportation (use of a car, bus, train, or other vehicles) facilitates the movement of people within the community, which allows them to engage in the activities that they need to do, they are expected to do, or they enjoy doing (Driving and Community Mobility, 2010).

Transportation Inequities

In North America, car culture has dominated for the past 100 years. Our cities and economies are built around driving. Consequentially, overwhelming majority of the population in Canada uses a car as their primary means of transit (Michelson & Lachapelle, 2016).

Moving from place to place without a car is challenging. There exists limited infrastructure for pedestrians and public transportation, especially in areas of lower population density like suburbs and rural areas (Blanke, 2007; Roberts et al., 2020; Seiler, 2009), making walking, biking, riding the bus or train difficult. These transportation inequities impact a wide range of individuals, albeit not uniformly. Those with higher incomes or lesser mobility constraints may not perceive the effects of limited mobility options. Conversely, individuals holding marginalized identities due to factors such as age, income, gender, race, immigration status, single parenthood, or disability are disproportionately affected (Bezyak et al., 2017; Bezyak et al., 2020; Lucas, 2016; Lucas; 2012; Luz & Portugal, 2020; Martens, 2016).

The circumstances in which individuals or communities face restricted availability of affordable, reliable, and accessible transportation options, especially public transit, is termed transport poverty (Luz & Portugal, 2020; Lucas, 2016). Lucas and colleagues explain that individuals are transport-poor if any of the following conditions are met: lack of transport options suitable for their physical condition and capabilities, unavailable or inaccessible transport options prevent them from reaching destinations necessary to fulfill daily activities, transportation expenses deplete the household's income to a level below the official poverty threshold, excessive time spent on travel, unsafe, hazardous, or unhealthy travel conditions (Lucas, 2016). This may include poor sidewalk infrastructure preventing those using mobility aids or those with poor balance arrive to the bus stop, a reliance on private transportation options like taxis and ride share services, and communities who spend several hours travelling for work and back.

The lack of adequate transportation infrastructure has serious consequences on individuals' well-being, quality of life, and the overall fabric of social interconnectedness. Without reliable means of mobility, individuals find themselves isolated, unable to access opportunities and resources enjoyed by others across economic, social, cultural, and political realms. This, in turn, contributes to social exclusion, a broad concept describing how certain individuals or groups find themselves unable to fully participate in various aspects of society often due to circumstances beyond their control (Luz & Portugal, 2020; Martens, 2016; Lucas, 2012).

Autism & Transportation:

Autism is a lifelong neurological condition marked by distinct differences and deficits in communication and behaviour. It's termed a spectrum due to the diverse range of symptoms, skills, and abilities exhibited by individuals who meet the diagnostic criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Indeed, each person's journey with autism is unique, encompassing a spectrum of strengths and challenges across various domains, including executive function, sensory processing, repetitive behaviours/interests, motor skills, perseverative thinking, social awareness, verbal and nonverbal communication, and information processing (NIMH, 2024; CDC, 2022).

Autistic individuals come from all types of backgrounds, and both countries have recorded incidence among all socioeconomic, racial, and ethnic groups. According to the data from the 2019 Canadian Health Survey on Children and Youth 2019, 1 in 50 Canadian children and youth aged 1 to 17 years are diagnosed with Autism (Public Health Agency of Canada, 2022). Estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network suggest about 1 in 36 children will be diagnosed with autism (CDC, 2024). As such, it is estimated that Autistic individuals make up 2-3% of the population in these countries.

Not all autistic individuals will face challenges in achieving independence and community engagement, but for many, these goals can be difficult to attain. Consequently, a substantial body of literature has emerged, pinpointing both facilitators and barriers and proposing interventions or supports. Within this literature, a significant focus has been placed on community participation, particularly in the realms of leisure, work, and education (Anderson et al., 2018; Barry et al., 2020; Cameron et al., 2022; Davy et al., 2022; Giummarra et al., 2022; Hedley et al., 2017; Nuske et al., 2019; Scott et al., 2019; Song et al., 2022).

Several of these studies highlight the pivotal role of transportation in enabling or hindering community participation and the transition to independent living for Autistic individuals. In these investigations, limitations in mobility and access to transportation emerged as significant barriers. Conversely, adequate access to various modes of transportation was found to enhance quality of life and was strongly linked to increased rates of community participation, employment, and educational attainment (Song et al., 2021; Wilson et al., 2021; Zalewska et al., 2016).

However, a recent needs analysis of Autistic adults in Canada revealed that many Autistic adults find it challenging to move around their community. Although their survey mostly reflected responses from Autistic adults with high levels of education and low support needs, more than 20% of individuals reported difficulty with community mobility and 35% of individuals reported needed to depend on others for their transportation needs. These figures are assumed to be lower than the actual reality since Autistic adults with high support or communication needs and with low levels of education and employment were underrepresented (Mackenzie-Salt et al., 2024).

Despite cited mobility difficulties in literature, very few studies have offered explanations or recorded descriptions of the barriers to transportation (Kersten et al., 2020; Lindsay, 2017; Wilson et al., 2018; Silvi et al., 2018). As such, little is known about the perspectives or needs of Autistic individuals.

Transportation Inequities as a Design Problem

Transportation inequities, including those concerning individuals with autism, underscore the critical intersection between design decisions and social inclusion. As mentioned above, the design of transportation infrastructure and policies significantly influences access to opportunities and resources, shaping the extent to which individuals with autism can participate in society. These inequities stem from choices regarding infrastructure development, resource allocation, and intended user demographics.

When considering the mobility challenges faced by Autistic individuals, it may be useful to frame participation issues within social model of disability (Woods, 2017). The social model of disability posits that disability is not an inherent trait of individuals but rather a result of societal barriers and inadequate accommodations (Marks, 1997). In essence, disability is framed as a design flaw within society rather than a characteristic inherent to individuals. As such, mobility issues among Autistic individuals can be structured as a design problem, where there is a mismatch between the affordances of our transportation systems and the needs of Autistic individuals. As such, this focuses on the design of buses, trains, sidewalks, roads, stations, signs, etc., rather than the qualities of Autistic people.

To effectively address these challenges, we must center our future design choices in the preferences, needs, and experiences of Autistic individuals. An inclusive design approach, which actively involves autistic individuals in the design process, emerges as a promising solution. Inclusive design approaches transcend the design approaches that rely on empathy and that place the designer as the expert by engaging designers to collaborate with, rather than simply design for, the end user. By collaborating with the end users and stakeholders throughout the design journey, inclusive design practices ensure that the resulting products are more relevant, usable, and safe (Inclusive Design Research Centre, 2018; University of Cambridge, 2017; Persson et al., 2015). Therefore, by co-designing alongside autistic individuals and drawing insights from their lived experiences, we can tailor our transportation design and policies to better cater to their unique needs, improving their mobility and quality of life.

Research Goals & Questions

Goals of the Study

To respond to the gaps listed above, the purpose of this study was to evaluate continued gaps since the completion of existing scoping reviews, guiding the subsequent studies and to identify possible areas for co-design.

Additionally, Canadian governments at all levels are implementing legislation to identify, remove, and prevent barriers for Autistic and disabled people across various aspects of public life. Indeed, laws like the Accessible Canada Act (Employment and Social Development Canada, 2022) and legislation like the National Autism Strategy (Public Health Agency of Canada, 2023) are far reaching and include transportation. However, despite this there remains a lack of specific policies supporting the transportation needs of Autistic adults (Dudley & Zwicker, 2016). As such, this research offers valuable insights which may inform policy and service decisions, sparking change and greater transport equity.

Research Question

This scoping review aimed to answer the following questions:

1. What are the experiences of Neurodiverse adults taking public transportation?
2. What recommendations exist to support Neurodiverse individuals?
3. What gaps exist currently requiring future research?

Methods

Search Strategy

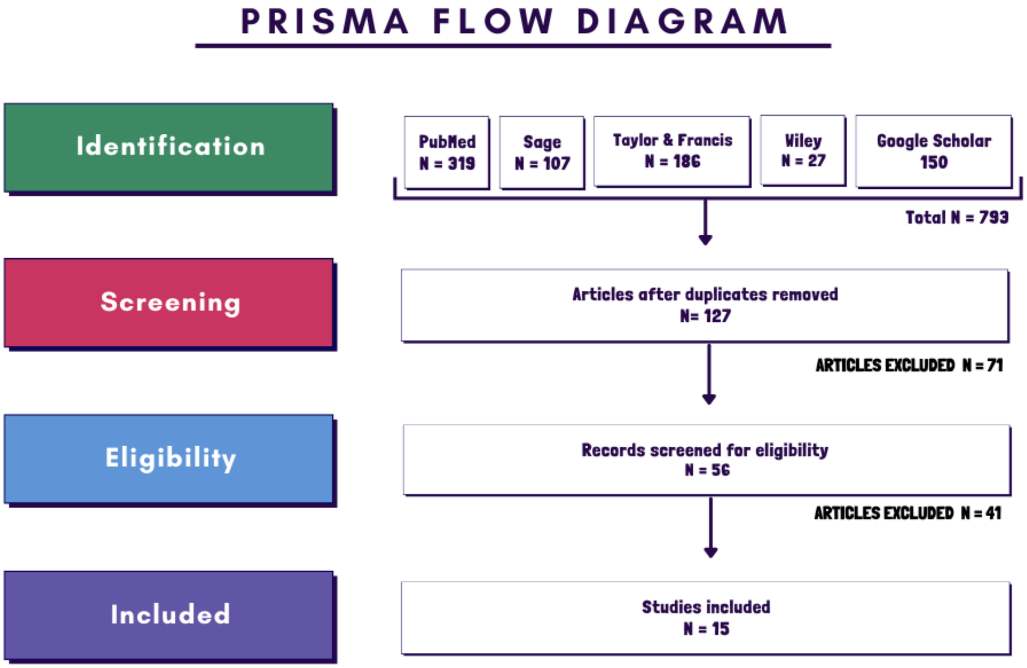
Between January and April 2022, scoping review was conducted following the methodology outlined by Mak and Thomas and by Arksey and O'Malley. The systematic search aimed to identify relevant literature published between January 2012 and January 2022. We searched multiple electronic databases including MEDLINE, Wiley, Taylor & Francis, Sage, and Google Scholar. The search strategy included keywords related to neurodiversity, community mobility, and related terms such as “Neurodiversity,” “Neurodivergence,” “Autism,” “Asperger's Syndrome,” “ADHD,” “dyslexia,”, “cognitive disability,” “learning disabilities,” “mobility,” “public transportation,” “bus,” “subway,” and "driving ". The term “train” was originally included but was removed later as irrelevant articles related to medical training were included in the results. Boolean operators "AND" and "OR" were used to combine search terms appropriately. The search strategy was tailored to each database to ensure maximum coverage of relevant literature. 793 articles were identified from the search.

Article Selection Criteria

After the initial search, duplicate records were removed using the reference management software Zotero, which resulted in 127 articles. The remaining articles were screened based on predefined inclusion and exclusion criteria. Articles were included if they addressed the experiences to community mobility among Neurodiverse individuals. Selected articles had to be published in peer-reviewed journals between 2012 and 2022 were considered eligible. Studies in languages other than English and studies focusing on other aspects of neurodiversity unrelated to community mobility were excluded, like work/school studies. Due to the limited results when limited to North America, the search strategy was not restricted by geographical location. The screening process involved reviewing titles, abstracts, and full texts as necessary. This resulted in a final selection of 56 articles

The search exclusion criteria were modified later to include only qualitative articles of Autistic individuals, as the literature was sparse for other neurodiversities. As such, articles that included cognitive disability, intellectual disabilities, learning disabilities, dyslexia, etc. were excluded. Additionally, scoping reviews, certain case-control, literature reviews, and certain case studies were removed. After reviewing all eligibility criteria, 16 articles remained.

Figure 1: Prisma Flow Diagram



Data Extraction & Synthesis

Data extraction was performed independently by the writer using a standardized data extraction form. The extracted data included author(s), publication year, study design, population characteristics, key findings related to community mobility barriers, and interventions, if applicable.

The extracted data were synthesized narratively to provide an overview of the existing literature on community mobility barriers among Autistic individuals. Themes and patterns across studies were identified and summarized to highlight key findings. The synthesis process involved organizing the data according to the objectives of the scoping review and identifying gaps in the literature.

As per scoping review guidelines, a formal quality assessment of individual studies was not conducted given the exploratory nature of the review. However, the methodological rigor and relevance of the studies included were considered during data synthesis and interpretation.

The reporting of this scoping review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines to ensure transparency and completeness. Please see the supplemental documents.

Results

Despite the emerging evidence in work-related research, little is known about the experiences and views of Autistic people regarding mobility. Indeed, only 15 studies have directly addressed travel experiences.

Driving

In studies looking at the transportation preferences of Autistic adults, travelling by car (by either driving or by being a passenger) was preferred (Falkmer, 2015). However, while many Autistic individuals mention they would like to secure a driver's license eventually, as it would provide them with a more comfortable environment along with more control and freedom over their travel, the rate of licensure is low. In fact, several studies estimate that only a third of autistic adults receive their full license (Huang et al., 2012; Lubin & Feeley, 2016), a result shared by a longitudinal study by Curry and colleagues in 2018. Moreover, of those who do drive, they drive less often than their neurotypical peers (Lubin & Feeley, 2016).

In some qualitative studies, Autistic individuals and their loved-one's report challenges with determining the speed of traffic, judging the distance of other vehicles, determining how to adjust driving with regards to signage (e.g. speed limit changes), maintaining attention on the road, following GPS directions or reading maps while driving, anticipating the actions of others, and reacting quickly to changes in the environment or ambiguous roadway situations, navigating accidents and dealing with law enforcement, (Almberg et al., 2015; Vindin et al., 2021; Ross et al., 2017; Myers et al., 2021; Lubin & Feeley, 2016; Kersten, 2020). As a result, of those who do have a license, neurodiverse individuals are more likely to drive only on familiar routes, with supervision, and more infrequently than their neurotypical peers (Feeley et al., 2015; Deka et al., 2016; Lubin & Feeley, 2016; Myers et al., 2021).

Additionally, driving is a complex goal-directed task that has high demands on perceptual, cognitive, and motor processes. Indeed, in order to drive one needs to switch between several subtasks (steering, signaling, braking, accelerating, etc.), while also reacting to the unpredictable changes in the environment (traffic, weather, etc.) seamlessly, which requires significant motor control, high levels of concentration, and quick processing skill (Ross et. Al., 2019). Numerous studies have indicated that Autistic individuals may struggle to learn and perform these skills due to differences in motor coordination, executive functioning, attention, ability to decipher certain social contexts (Classen et al., 2013; Cox et al., 2012; Daly et al. 2014; Monahan et al., 2013; Patrick et al. 2018; Ross et al., 2015).

However, in their 2018 article, Ross et. al. reported that although there existed some group differences, autistic individuals did not consistently underperform in comparison to neurotypical peers. In fact, autistic drivers were just as good or even outperformed their peers on certain tasks. This suggested that Autistic individuals could be considered as capable drivers.

Public Transit

Public transit systems (e.g. buses, trains, tram, subway/metro and ferry services) have been reported to be important for independent mobility and to be an affordable alternative to driving for Autistic individuals (Falkner, 2015; Lubin & Feeley, 2016; Kersten 2020). Like driving, using public transit is a complex task with many steps and unpredictable variables. For example, one needs to arrive at the station or stop, purchase a fair, orient oneself by using different signage, board and alight the vehicle, and share space with others. As such, individuals that use public transportation need to plan, problem-solve, socialize, and manage sensory stimuli (Haas et al., 2017).

Thus far, a handful of studies have explored the experiences of Autistic individuals. The majority of these studies reveal that many Autistic individuals have difficulty using the current public transportation systems. Autistic individuals reported concerns about navigating new spaces, changes in service or schedules, difficulty tolerating smells, sounds and being in close proximity to other passengers, understanding online and written information (Lubin & Feeley, 2016; Haas, 2017; Feeley et al., 2015; Lim et al. 2021).

Both parents and Autistic young adults expressed concerns about their safety after experiencing negative interactions with other passengers and transit staff. As such, many participants felt the need to change their behaviour (masking) or to be hypervigilant to read body language and learn the invisible social rules. Moreover, many participants reported anxiety and exhaustion when taking public transportation (Deka, 2016; Lubin & Feeley, 2015, Kersten, 2020 A; Kersten, 2020 B; Lim et al., 2021).

In addition to the factors above, a lack of affordable options, a lack of available transportation options, and a lack of training were also identified as barriers (Feeley et al., 2015).

However, some individuals report no challenges with these systems and feel confident in their use (Falkner et al., 2015).

Walking in the Community

Walking can be an important means of mobility for many Autistic individuals to increase their independence. However, few destinations can be reached by walking in North American cities, rural areas, or suburban communities. Indeed, destinations may be far, the route may lack walking infrastructure (e.g. sidewalks), or there may be other barriers that make the journey un-walkable (e.g. highways) (Lubin & Feeley, 2016). Walking may not be an option for some neurodiverse individuals as well due to challenges in way finding and in navigating busy intersections, to physical barriers and to safety concerns (e.g. dangers associated with walking in unsafe neighbourhoods at night) (Lubin & Feeley, 2016; Kersten, 2020).

Passengers

Because of difficulties with driving and with taking public transportation, an overwhelming majority of Autistic individuals depended on loved ones for rides. While some mention that they are satisfied with this arrangement, others found it problematic. They are reliant on the schedules of others, which means they cannot engage in activities when and how they would like. Others mention that they felt like they were a burden, as those who drive them may experience financial losses and emotional stress (Lubin and Feeley, 2016; Deka, 2016).

Discussion

Knowledge Gaps

The literature reviewed underscores significant challenges in understanding mobility issues faced by Autistic individuals. However, the evidence base is notably sparse in both quantity and depth. A mere 17 studies have delved into the driving and public transportation experiences of Autistic individuals, with a predominant emphasis on driving, aligning with prior systematic reviews by Kersten et al. (2020) and Lindsay (2017). Regrettably, many of these studies relied on proxies such as parents, healthcare practitioners, and driving instructors, rather than directly engaging with Autistic individuals themselves, leaving a conspicuous void in our comprehension of their desires and perspectives.

The bulk of community mobility research concerning Autistic individuals has predominantly unfolded in car-centric nations like the United States and Australia. Indeed, 83% of studies (N=14) were conducted in these regions, often by recurring research teams. As such, there exists a notable gap of insights into the unique transportation experiences of Autistic individuals in other nations with more walkable cities or cities with greater access to alternative modes of transit, like buses and bikes.

While Canada's transit infrastructure shares similarities with both Australia and the United States, suggesting that some findings may be applicable, it's crucial to acknowledge the potential influence of political and environmental factors. As such there remains a gap in knowledge regarding the specific experiences of Autistic Canadians, which are intricately shaped by unique federal, provincial, and municipal policies, alongside the country's distinct climate.

Given the historical dominance of car culture in the countries where these studies were conducted, it's unsurprising that the focus has heavily leaned towards driving. However, what's unexpected is the scarcity of qualitative methodologies employed. The literature predominantly favors quantitative approaches, often utilizing simulators, to describe and explain driving challenges or disparities between neurotypical and Autistic drivers. Notably, nine studies were excluded from this analysis due to their use of a case-control design, echoing findings from Wilson et al.'s scoping review, completed in 2018.

Overall, there remains a considerable gap in understanding the preferences and needs of the primary users, hindering the creation of effective, inclusive, and relevant mobility solutions.

Proposed Solutions:

In the identification process of this literature, 24 studies were identified suggesting and testing different mobility interventions for Autistic and other Neurodivergent individuals. As mentioned above these were excluded from the scoping review as they did not follow a qualitative design.

A superficial review of these articles was completed by reading their abstracts and the literature appears to abound with different suggestions to address the inaccessibility of our current transit systems. Indeed, these studies explored a range of solutions which included traffic training, development of applications, creation of monitoring tools, specialized teaching, virtual reality and the use of autonomous vehicles (Cano et al., 2016; Cecchini et al., 2018; Dicianno et al., 2021; Gallup et al., 2015; Haveman et al., 2013; Kassens-Noor et al., 2021; Kelley et al., 2013; Kersten et al., 2021; Lindsay, 2020; Lindsay and Lamptey, 2019; Livingstone-Lee et al., 2014), McMahon et al., 2015; Miller et al., 2020; Neven et al., 2017; Pfeiffer et al., 2020; Precin et al., 2012; Price et al., 2017; Rezae et al., 2020; Rezae et al., 2021; Schmidt et al., 2020; Simões et al., 2018; Stock et al., 2013; Wolf-Branigin et al., 2013).

However, these studies often adopted a prescriptive approach. Rather than actively involving Autistic individuals in the design process, researchers and designers seem to frequently treat Autistic individuals as mere data points or as passive subjects. Indeed, many of these studies used case-control or pre-post study design, analysing the data with only quantitative analyses, neglecting potentially valuable insights from the Autistic users. This lack of direct engagement raises significant concerns regarding the validity and feasibility of proposed solutions. Indeed, without soliciting the opinions and perspectives of Autistic individuals, there is a risk of tokenism, where their involvement is seen as minimal or superficial.

Part 2: Proposal For Future Research

Goal of the Study

The scoping review above revealed that while there are significant barriers to community mobility among Autistic individuals, there are few studies directly investigating them explicitly. No study was identified in Canada. Therefore, to respond to this need for greater knowledge, the writer has proposed a two-part qualitative study focusing on the public transportation experiences of Autistic young adults in Toronto.

A Participatory Approach

A Lack of Representation in Autism Research.

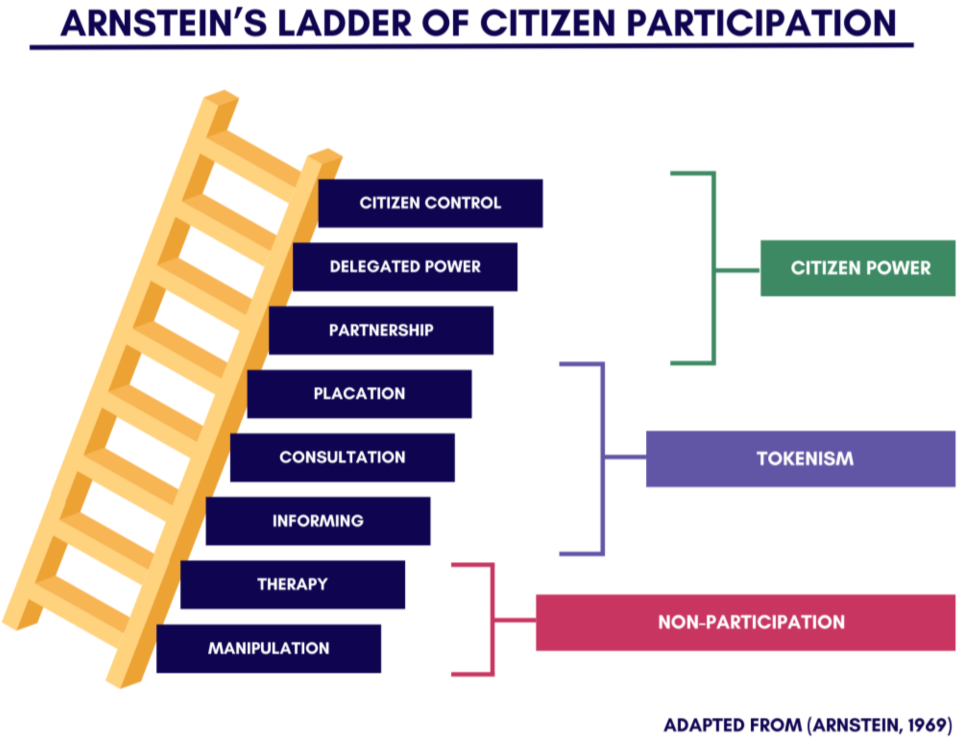
Despite being lifelong conditions, most of the research regarding autism focuses on etiology, childhood implications and therapies and much of this research privileges non-Autistic perspectives (non-autistic parents, healthcare professionals, researchers, etc.) (Fletcher-Watson et al., 2019; Kwe, 2020). Indeed, of the literature that focuses on the experiences of autistic adults, few studies use a participatory approach. Some scholars have explained that this is due to deeply ingrained beliefs surrounding the abilities (and inabilities) of Autistic individuals among researchers and non-autistic people (Nicolaidis et al., 2019; Kwe 2020). This systematic exclusion of Autistic voices constitutes a form of ableism as it communicates that Autistic individuals are unable to advocate for themselves or that their voices are unimportant (Botha & Cage, 2022).

Because the voices of Autistic individuals have been excluded from research, numerous stereotypes have been propagated, which have contributed to the hostility of certain spaces (Milton, 2014). As such, there have been calls within the autistic and neurodiverse community for more authentic representation. Participatory and emancipatory research methods is one way to bridge this gap, as these research models place participant, in this case neurodiverse voices at the forefront.

Participatory Approach & Autistic Community

Participatory research methods center on the active involvement of participants in shaping the research process, allowing them to determine what is studied and how it is studied. This approach emphasizes power-sharing and collaboration, enabling participants to make meaningful choices and decisions through collaboration, co-creation, and co-design (Cornwall & Jewkes, 1995; Cornish et al. 2023). Requires a recognition of power imbalances between researchers and community partners. Power varies depending on the type of participation. This is conceptualized in Arnstein's Ladder of Participation. In this model, the lowest power is non-participation, followed by tokenism, and citizen power/shared power (Arnstein, 1969).

Figure 2: Arnstein's Ladder of Participation:



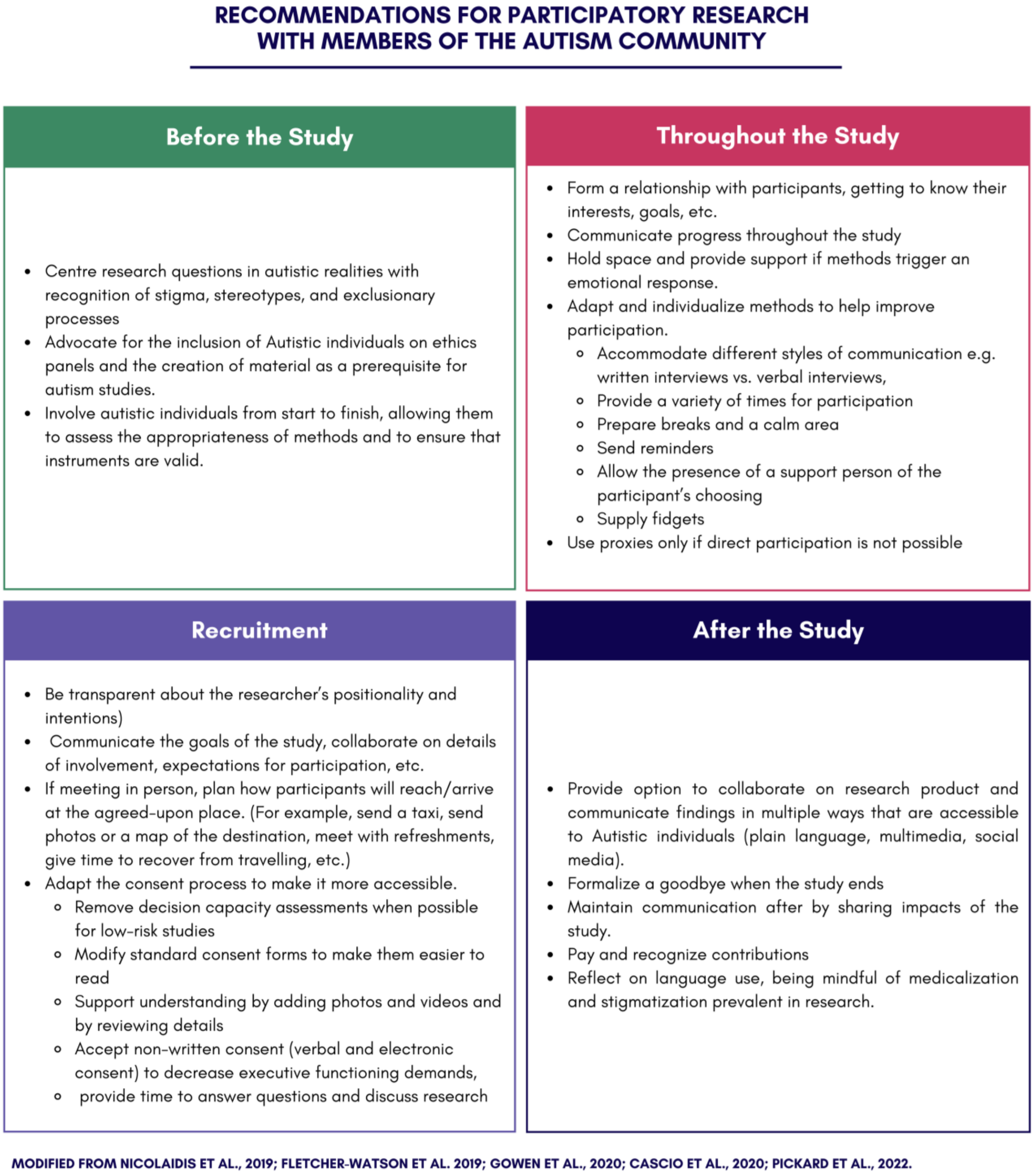
Participatory research has been shown to yield numerous benefits. By striving for genuine partnership rather than mere consultation, participatory research empowers participants to shape the study, leading to outcomes that are more relevant, impactful, and less likely to cause harm. Systematic reviews further highlight advantages such as improved recruitment, retention, research design, measurement, and funding acquisition for researchers, and enhanced research-related skills, leadership, and confidence for community members. Moreover, Botha & Cage (2022) observed that participatory approaches to Autism research are less ableist, safer, and more aligned with the goals of the autism community compared to traditional research methods.

Despite these benefits, implementing a participatory approach can be challenging due to various factors, including logistical complexities, differing priorities, and communication issues. As such, it is recommended that researchers employing a participatory approach be transparent about the partnership goals, define roles clearly, create an environment suitable for good communication and power-sharing, develop strategies for building and maintaining trust, and to develop mutually beneficial relationships by adequately recognizing and compensating participants for their involvement in the study (Duea et al.m 2022).

However, when conducting participatory research with Autistic individuals, additional factors must be considered, including addressing the double empathy problem and communication barriers, mitigating the impact of negative bias that exists in medicine and research, and adapting for different ways of working. To navigate these complexities, guidelines specifically tailored for conducting participatory research with autistic individuals have been developed (Nicolaidis et al., 2019; Fletcher-Watson et al. 2019; Gowen et al., 2020; Cascio et al., 2020; Pickard et al., 2022).

In implementing a participatory approach, we have integrated many of these recommendations into the proposed study. These include consultation with industry partners, the creation of an advisory committee, the clear communication of goals and expectations, the individualization and adaptation of methods, and a robust knowledge translation strategy with various research products. These design choices are integrated and explained throughout the following sections.

Figure 3: Recommendation for Conducting Participatory Research with Members of the Autism Community



RECOMMENDATIONS FOR PARTICIPATORY RESEARCH WITH MEMBERS OF THE AUTISM COMMUNITY

Before the Study

- Centre research questions in autistic realities with recognition of stigma, stereotypes, and exclusionary processes
- Advocate for the inclusion of Autistic individuals on ethics panels and the creation of material as a prerequisite for autism studies.
- Involve autistic individuals from start to finish, allowing them to assess the appropriateness of methods and to ensure that instruments are valid.

Throughout the Study

- Form a relationship with participants, getting to know their interests, goals, etc.
- Communicate progress throughout the study
- Hold space and provide support if methods trigger an emotional response.
- Adapt and individualize methods to help improve participation.
  - Accommodate different styles of communication e.g. written interviews vs. verbal interviews,
  - Provide a variety of times for participation
  - Prepare breaks and a calm area
  - Send reminders
  - Allow the presence of a support person of the participant's choosing
  - Supply fidgets
- Use proxies only if direct participation is not possible

Recruitment

- Be transparent about the researcher's positionality and intentions)
- Communicate the goals of the study, collaborate on details of involvement, expectations for participation, etc.
- If meeting in person, plan how participants will reach/arrive at the agreed-upon place. (For example, send a taxi, send photos or a map of the destination, meet with refreshments, give time to recover from travelling, etc.)
- Adapt the consent process to make it more accessible.
  - Remove decision capacity assessments when possible for low-risk studies
  - Modify standard consent forms to make them easier to read
  - Support understanding by adding photos and videos and by reviewing details
  - Accept non-written consent (verbal and electronic consent) to decrease executive functioning demands,
  - provide time to answer questions and discuss research

After the Study

- Provide option to collaborate on research product and communicate findings in multiple ways that are accessible to Autistic individuals (plain language, multimedia, social media).
- Formalize a goodbye when the study ends
- Maintain communication after by sharing impacts of the study.
- Pay and recognize contributions
- Reflect on language use, being mindful of medicalization and stigmatization prevalent in research.

MODIFIED FROM NICOLAIDIS ET AL., 2019; FLETCHER-WATSON ET AL. 2019; GOWEN ET AL., 2020; CASCIO ET AL., 2020; PICKARD ET AL., 2022.

Development and Validation of Methods:

Following participatory research models, the development of our research methodology was an iterative process characterized by collaboration, feedback integration, and methodological refinement with key stakeholders. Initially, we recognized the necessity of establishing a framework to guide our inquiry, leading to the creation of a comprehensive Journey map reflecting a typical ride on Toronto's public transit systems. This map allowed us to identify key areas of interest and to structure our conversations with participants.

Concurrently, substantial effort was directed towards the fabrication of a sound methodology and materials. This included the development of a website (for both recruitment and information dissemination), and the creation of consent protocols, demographic inquiries, recruitment material (social media posts, posters, etc.).

Central to the refinement of our methods was the invaluable input and guidance provided by our industry partners and advisors. Through in-depth discussions with individuals from organizations such as the TTC, Metrolinx, and the City of Toronto we were able to review our materials and methods, ensuring their alignment with real-world practices and objectives.

To ensure that our methods and our materials were reflected the needs of the Autistic community, we enlisted the support of advisors with lived and living experience and expertise in public transit delivery or navigation support. In the fall of 2023, 5 advisors were identified. However, due to delays in research funding, 2 advisors (a parent of an Autistic youth / participatory researcher and an individual with lived experience) were unable to participate. 3 Advisors (1 Autistic youth with expertise in inclusion, diversity, equity, and accessibility, a mobility therapist, a leader of a national advocacy group and a professor of public policy) were solicited to provide feedback on the materials and methods.

Following the feedback and ongoing discussions, an application to the research ethics board at OCAD University was submitted. In January 2024, we received ethics clearance from the Research Ethics Board at OCAD University (REB #: 2024-01).

Methods

Determining the Sample

Specifically, we aim to recruit individuals who self-identify as Autistic between the ages of 18 and 35 living in the greater Toronto area. Since we are studying experiences taking public transportation, participants will be encouraged to have frequent experience taking the subway, buses, street cars, trains, public bicycles, or other modes of transit in the city.

Unfortunately, individuals who have experienced significant head trauma in the past 5 years will not be invited to participate in the study, as their abilities will likely change over time. Similarly, people with serious mobility restrictions will also be excluded from the study, as mobility restrictions fall outside the scope of this study and have been well studied.

Certain accommodations will be available to participants to help improve their participation and their ability to sign consent. For example, the option to invite a support person of their choosing, reminders, preparatory meetings/videos, and alternative interview methods will be provided. This is done to ensure we can limit the barriers to participating in research for members of the Autism community with greater support needs. However, if the supports available in the study are not enough to allow a participant (e.g., to provide a clear understanding of the study/consent), the individual will not be able to take part in the study. Lastly, those without smartphones and access to a computer will not be able to participate as many of the activities require them.

We believe that a sample size of 12-18 participants will be adequate to respond to our research question with reasonable validity and generalizability. Indeed, although the sample size of qualitative studies varies, (Vasileiou et al., 2022), 9 to 17 interviews have been shown to be sufficient in achieving saturation (Hennink & Kaiser, 2022; Hennink et al., 2017). This amount is also appropriate for the type of analysis performed (thematic). Pragmatically, this size was also chosen given the resources available to the writer, given the time and funding constraints of the project.

Self-identification was chosen instead of formal diagnosis as the inclusion criterion since several studies have revealed that adults who self-identify as autistic have similar lived experiences to those with a formal diagnosis of autism. Additionally, self-identification was chosen to limit the barriers to participation since there are numerous obstacles to receiving a formal diagnosis, including attitudes of medical professionals, wait times, and costs, especially among female individuals (Overton et al., 2023).

Lastly, young adults 18-35 were chosen to participate in this study as they are working age adults and are likely to need public transportation to get from place to place, as indicated by the 2016 Canadian census data (Winters & Hosford, 2022).

Recruitment

Selecting Recruitment Methods

Social media has been shown to be extremely effective as a means of recruitment. Indeed, advertising on Facebook has been shown to be more time- and cost-effective than traditional research advertising strategies (Thornton et al., 2016; Ahmed et al., 2020). This can be explained by the fact that high rates of young people and individuals with autism, along with their family members, utilize social media for online support and community connection, fostering meaningful interactions and accessing resources that contribute to their well-being and sense of belonging (Cole et al., 2017; Hudson et al., 2023; van Driel et al, 2023).

However, social media as a means of convenience sampling alone may not be enough to get a representative sample. Indeed, relying on convenience sampling alone may introduce sampling bias as there is evidence that women, individuals with high levels of education, individuals with high rates of employment, and individuals with fewer support needs are more likely than other autistic individuals to respond to research invitations (Rødgaard, 2022). Since the Autism population is heterogeneous (Massi et al., 2019), it is important to have a diversity of identities to ensure that the results are not only valid but also generalizable.

To increase the diversity of our sample, we have also included purposive sampling methods, using snowball, criterion, and critical case sampling. After identifying individuals are potentially missing from the sample, soliciting the support of participants and community organizations can be helpful in recruiting them (Naderifar et al., 2017). Indeed, individuals that are missing from the sample may be more likely to participate if they are recruited by individuals they know and trust.

Considering these findings, a mixture of recruitment methods was selected to ensure a diversity of individuals with different support needs and sufficient reach. As such, our recruitment/sampling strategy includes convenient sampling through posting on social media and placing posters at local universities and schools, and purposive sampling through collaboration with local community organizations and participants.

Creation of Recruitment Materials

Posters and social media posts have been created using Canva, a design platform. Pictures of the Toronto Transit Commission (TTC) were used to immediately convey the subject matter of the study. All essential information about the study, such as its purpose, eligibility criteria, and how to participate, was also included. Special attention was also spent on including jargon-free language to ensure accessibility for individuals with diverse communication styles and abilities.

To streamline the process of accessing more detailed information or contacting the research team, QR codes or links to the study website/email are incorporated into the recruitment materials. We hope that these will allow prospective participants to conveniently access additional resources or reach out for further assistance with minimal effort, enhancing the overall user experience and encouraging engagement.

Before finalizing the recruitment materials, they were carefully reviewed and validated by advisors and supervisors to ensure that the content was appropriate, and effective in resonating with the target audience while adhering to ethical guidelines and best practices in research communication.

The student investigator plans to circulate the posters at different Toronto universities and college campuses and to share them with his online network. In addition to finding Facebook, Instagram, and LinkedIn groups/pages on Autism and research, members of the Autism Alliance have offered to circulate the posters to local community organizations and advisors have offered to recruit potential participants from their own personal networks. Lastly, Quoi Media, a boutique communications firm in Canada specializing in public policy and knowledge translation of academic studies, has provided a quote for additional social media outreach.

Screening Procedures & Supports

Interested participants will be invited to email the research team at a shared email address to set up a date using a scheduling platform, like Calendly. This process was selected to help ease the organization and communication for both the researcher and the participants. Specifically, the research team identifies times that they can conduct the interviews, and participants can then select the times that they are available before it is automatically added to Google, iCalendar, and Microsoft Outlook calendars.

Before the first meeting, participants will be requested to review the consent form and the website to ensure that they are informed about what is expected for their participation and about the risks and benefits. Several measures have been taken to help communicate these expectations, from ensuring that the language in the consent form uses plain language and that there are short videos describing important information available on the website.

Participants will also be asked to complete a demographic questionnaire to ensure they meet the inclusion and exclusion criteria prior to the first meeting. This questionnaire was validated by advisors and is planned to be sent by Microsoft Forms. Microsoft Forms was selected due to its availability, user-friendly interface, and security. Additionally, it was also chosen because this program automatically organizes and stores the collected data in a structured format, simplifying data management and analysis.

The initial meeting serves as a pivotal step in our selection process. Led by the student researcher or a research assistant, this session gives participants an opportunity to seek clarification and openly discuss expectations. These discussions will enable our research team to gauge participants' comprehension, identify potential supports, reaffirm the voluntary nature of participation, and secure written or recorded consent. Individuals unable to provide consent or who do not meet the inclusion criteria will be informed of their ineligibility to participate.

Data Collection & Analysis:

Following the selection process, the research team will conduct semi-structured interviews via Microsoft Teams or by email. If participants select a Microsoft Teams interview, they will be sent an invitation for a meeting lasting a maximum of 90 minutes with the list of potential interview questions. This meeting will be recorded to ensure accurate data collection, as the interview can be transcribed. If participants select to complete an email interview, they will be sent the same list of questions to respond to. If questions remain unanswered or if clarification is needed, they will be contacted to answer follow-up questions.

Providing two options is anticipated to be an important accommodation as it can decrease barriers to participating for those with difficulties with social communication. Indeed, providing the option of email interviews alongside video-conferencing interviews can be particularly beneficial for autistic individuals with communication challenges or social anxiety for several reasons. Firstly, email interviews offer a more asynchronous and text-based communication format, which may reduce the pressure and anxiety associated with real-time interactions. This allows individuals to take their time to process questions and formulate responses at their own pace, without the added stress of navigating social cues or non-verbal communication. Additionally, email interviews provide a sense of control and autonomy over the communication process, as individuals can choose when and where to respond, creating a comfortable and familiar environment. Moreover, the absence of face-to-face interaction can alleviate sensory overload and minimize distractions, enabling individuals to focus more effectively on articulating their thoughts and experiences.

Following the first interview, participants will be requested to take photos, videos or audio recordings of their commutes with their smartphones or cameras over a 2 to 3-week period. During this period, participants will be provided with prompts to help to guide their recordings.

After participants have taken their photos and recordings, they will be requested to submit them to the research team before completing a second round of interviews to expand on the themes and narratives from their first interview. This second interview is meant to validate their narratives, ensuring the trustworthiness and credibility of the data collected. As with the first interview, participants can complete either a Microsoft Teams interview lasting 90 minutes (about 1 and a half hours) or an email interview with potential follow-up.

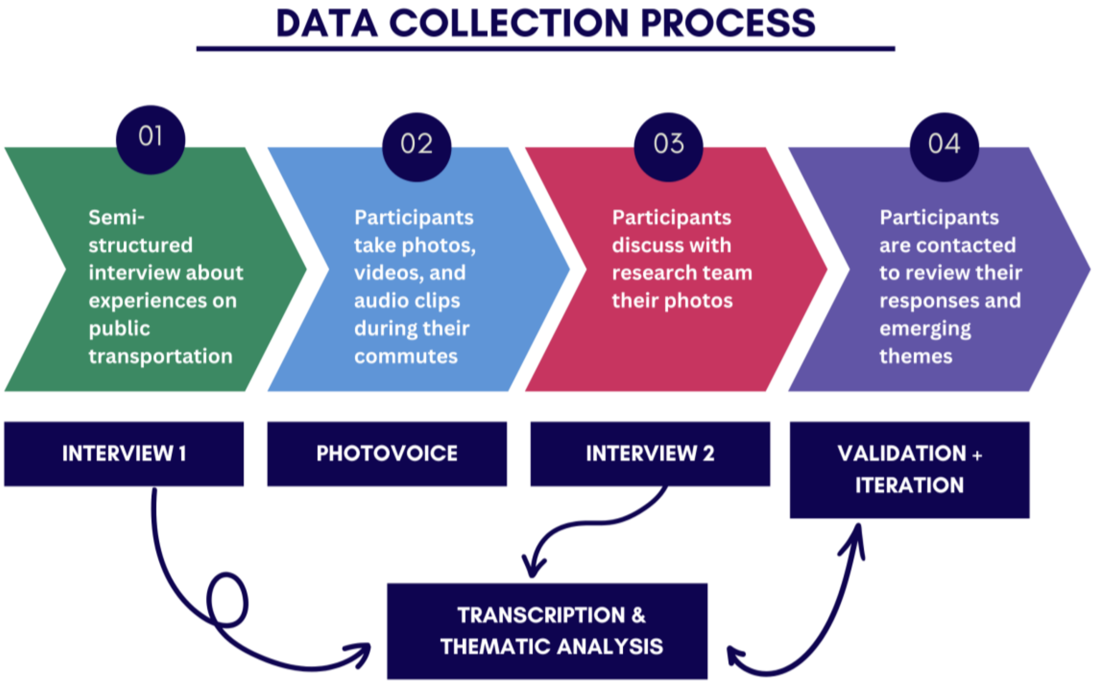
A last meeting will be held with participants, to present the initial findings, allowing them an opportunity to validate their responses or to critique the themes presented. This meeting will also serve as an opportunity to discuss next steps and administrative details, like compensation.

Following data collection, responses will be transcribed using voice-to-text software and then analyzed using thematic analysis. Indeed, facilitated by a qualitative data analysis program, NVivo, keywords and codes will be identified from key quotes before being grouped into themes.

Thematic analysis was selected for its compatibility with the exploratory nature of the research objectives and the writer's constructivist perspective. As the study seeks to gain a comprehensive understanding of the diverse experiences, thematic analysis offers a systematic yet flexible approach to data interpretation, allowing for the identification of emergent themes and patterns that may not have been predetermined. Moreover, thematic analysis facilitates the in-depth exploration of qualitative data while remaining accessible to researchers across various disciplines and levels of expertise. This inclusivity aligns with the interdisciplinary nature of the research and ensures that the analysis remains grounded in the lived experiences of participants (Naeem et al., 2023).

Although this study primarily uses interviews as the main method of data collection, it also benefits from aspects of the photovoice methodology. Photovoice is a research methodology whereby participants record and reflect on their experiences through photographic techniques to promote critical dialogue and knowledge translation (Wang & Burris, 1997). Photovoice activities have been successfully conducted with autistic and neurodivergent individuals (Catalani & Minkler, 2010; Ha & Whittaker, 2016; Heffron et al., 2018; St. John et al., 2021; St. John et al., 2022) and have been shown to facilitate communication and enhance meaningful participation. (Do et al., 2021). By allowing participants to express their perspectives through photography, Photovoice facilitates a deeper understanding of the participants' realities while promoting meaningful engagement. Lastly, Photovoice was chosen due to its alignment with a participatory research framework. Participants are empowered to select and capture images of their choice, thereby actively shaping the research outcomes. Indeed, this bottom-up approach contrasts with traditional top-down methodologies, fostering a more collaborative research process where participants have agency in defining the research agenda and contributing to knowledge generation (Liebenberg, 2018).

Figure 4: Data Collection Process



Enacting The Principles of Research

In conducting this research study, significant reflection has been dedicated to the enactment of the core values outlined by the Tri-Council Research Ethics guidelines of Canada, as well as the principles of participatory research. In this section, we explain how we have embodied the values of Respect for Persons, Concern for Welfare, and Justice (Canada, 2022).

Respect for Persons

Respect for Persons encompasses honoring individuals' autonomy, safeguarding those with evolving or impaired autonomy, and upholding their volition and consent. Autonomy involves the ability to deliberate on decisions and act upon them freely. Respecting autonomy entails giving due regard to an individual's judgment and ensuring freedom of choice without interference. Autonomy is influenced by various social and environmental factors. As such, it is important to reflect on these factors to ensure that participants can provide their voluntary, informed, and ongoing consent (Canada, 2022).

Consent & Decision-Making Capacity:

Questions around who can offer consent occur often in Autism Research (Fisher, 2003; Harris, 2003; Cascio et al., 2020; Botha & Cage, 2022; Pellicano et al., 2014). Naturally, given the history and perpetuation of transgressions against disabled and Neurodivergent individuals in research and healthcare settings, there are concerns about the risks of exploitation and coercion and there exist protocols to protect these individuals (Waltz, 2023; Evans, 2020; Cascio et al. 2019; Chapman & Carel, 2022; Carlson, 2013).

However, these protective measures can also serve as barriers to participation, resulting in harm. As indicated above, the systematic exclusion, underrepresentation, and misrepresentation of Autistic individuals has led to perpetuation of stereotypes, misaligned priorities, and discrimination.

As such, the risks associated with participation need to be balanced with the need for autonomy, inclusion and justice. Unnecessarily excluding participants from research, using proxies when information can be taken directly from Autistic individuals, and denying individuals to make decisions about their participation is a violation of their rights (McDonald & Raymaker, 2013).

We must not automatically assume that Autistic individuals have impaired decision-making capacity. Nor should we require Autistic individuals to prove their competency through capacity assessments simply due to their diagnostic label. Doing so is a form of discrimination. As such, capacity should be assessed on a case-by-case basis, like in the general population. In low-risk studies, like this, there is precedent of even forgoing these assessments (Nicolaidis et al., 2020). In cases where a participant's decision-making capacity is unclear, supports should be put in place to enhance understanding and to assess comprehension. With this in mind, researchers and ethics boards have the responsibility to provide the necessary support and accommodations to make consent processes accessible to a range of abilities.

For the present study, we have adapted the traditional consent process to improve accessibility using several guidelines for the best practice of participatory research with Autistic adults (Nicolaidis et al., 2020; Gowen et al. 2020). Indeed, we have produced consent forms and a website to explain each aspect of the study. These materials were written in plain language and include videos and photos to help with comprehension. As mentioned above they were reviewed by stakeholders to also ensure that the language and useability were adequate. Beyond the materials, we have planned for meetings to review the details and to explore expectations. Since providing written consent can be challenging, we have planned to record verbal consent and to use online software, like DocuSign, removing the need for printing, signing, and returning the form.

Given the low level of risk associated with this study, we assume that participants possess adequate decision-making capacity. Participants demonstrate this capability by actively and independently contacting the research team and navigating through online resources and public transit, often involving decisions comparable to or even surpassing those involved in our study. Hence, conducting a formal assessment of decision-making capacity was deemed unnecessary and inappropriate. Nonetheless, while a comprehensive evaluation will not be conducted, we have provided opportunities for participants to familiarize themselves with the study's objectives and procedures, aligning with standard practices in qualitative research.

Volition:

Numerous measures have been implemented to mitigate the risk of coercion and underscore the voluntary nature of participation. Participants are explicitly informed of their right to withdraw from the study at any point without penalty. The possibility of withdrawing is communicated prominently on the research website, in informational videos, and within the consent form. Additionally, the voluntary nature of participation will be reiterated at the outset of all meetings to reaffirm participants' autonomy. Should participants choose to retract their involvement, they are encouraged to inform the research team. Participants can choose to provide their reasons for withdrawal. If provided, the reason will be recorded for study documentation.

While data collected will be retained for research purposes unless otherwise requested, participants are assured that they retain the option to request deletion of their information, although this cannot be accommodated once the analysis phase has commenced. Before the research team starts the thematic analysis, participants will be contacted, allowing them to retract their input.

Lastly, payment for participation was determined by compensation guidelines outlined by national research organizations (Community of Practice, 2024). These amounts have been determined to be fair and noncoercive, thus further supporting the ethical principle of volition in research engagement.

Justice

Ensuring fairness and equity requires a thoughtful examination of vulnerability. Vulnerability often stems from factors such as limited decision-making capacity or constrained access to social resources like rights, opportunities, and power. Historically, certain individuals or groups, such as children, the elderly, women, prisoners, and disabled individuals, have been particularly vulnerable in research contexts. To prevent inequity, participation criteria must align closely with the research question and must be critically assessed, ensuring that no group is unfairly excluded from the research benefits and that exclusions are neither arbitrary nor irrelevant (Canada, 2023). As mentioned above, individuals with Autism have been unjustifiably excluded from research participation due to negative bias and overly stringent safeguards.

In this study, extensive consideration was given to the dynamics of power between researchers and participants and to the criteria for exclusion. As mentioned throughout this paper, we are following a participatory approach and implementing several adaptations to ensure the inclusion of individuals with a diverse range of abilities. Exclusions were intentionally limited to individuals with significant brain injuries within the past five years, those with mobility restrictions, and those residing outside of the Greater Toronto Area. Brain injuries were excluded due to potential changes in experiences over the study duration. Individuals residing outside of the GTA and those using mobility devices were excluded, as their experiences extended beyond the scope of the study.

Concern for Welfare

Concern for welfare encompasses a comprehensive consideration of factors that impact individuals' physical, mental, and spiritual well-being, as well as their economic and social circumstances. This includes not only their immediate health but also their overall quality of life, encompassing aspects such as housing stability, employment opportunities, sense of security, family dynamics, community engagement, and social inclusion. Additionally, the control of personal information and privacy rights plays a crucial role in promoting individuals' welfare by safeguarding their autonomy and dignity (Canada, 2022).

Benefits & Harms

Conducting a thorough cost-benefit analysis is imperative to evaluate potential risks and benefits associated with the study (Coleman, 2021). While the research poses minimal physical risks to participants as it primarily involves reflective activities on their daily experiences, it's important to acknowledge the inherent risks associated with urban transit activities. These may include navigating busy streets, boarding and disembarking from vehicles, maintaining balance on moving vehicles, and possible physical interactions with other passengers. These risks, while not specific to the study's target population, are intrinsic to urban living and engaging with public transit systems.

Moreover, participants may encounter emotional discomfort or distress when recounting their experiences with the public transit system. Discussing challenging or traumatic events has the potential to evoke difficult emotions and may even lead to retraumatization (Isobel, 2021).

To mitigate these risks, proactive measures will be implemented to provide participants with a safe and supportive environment. In our study, this includes offering access to psychological resources and support services, establishing community guidelines to foster a respectful and inclusive space, and providing clear avenues for participants to exit the study if they feel unsafe or overwhelmed.

Regarding benefits, participants will receive financial compensation for their involvement in the study, following best practices observed in participatory and autism research (Community of Practice, 2024). Compensation, set at $50 per session in gift cards, aims to recognize participants' time, effort, and contribution to the research process. This means that participants will earn a maximum of 150$. Gift cards were selected to decrease the administrative burden on participants, to decrease the wait between participation and payment, and as they are nontaxable, meaning that they would not affect disability benefits.

Additionally, participants may potentially benefit from other opportunities, such as receiving a letter of reference or even co-authorship/presentation if the co-designed project is published or presented at conferences. These benefits are intended to acknowledge participants' valuable contributions and may open doors to further research involvement or professional development opportunities.

Lastly, for many Autistic individuals, the possibility of making a positive impact by participating in research is a benefit. Many autistic individuals mention that they enjoy learning about and contributing to their community, beyond the desire to feel heard and understood (Gowen, 2019; Pickard et al., 2022; Pellicano et al., 2022). While the study holds the potential to inform future urban planning and transit decisions, it's important to manage expectations regarding its direct impact on systemic change within transit systems. Despite confirmed partnerships with organizations like the TTC and Metrolinx, there is no guarantee that the findings will directly influence policy or practice. As such, it's essential to contextualize the potential benefits and aspirations of the study within realistic parameters to ensure transparency and manage participants' expectations accordingly.

To ensure the safety and appropriateness of our methods, we collaborated with research experts and advisors with relevant lived experiences. Their feedback and perspectives influenced the study's design, ensuring the integration of necessary safeguards and support mechanisms. Additionally, this proposal was submitted to OCAD University's research ethics board, which assessed the risks and benefits involved and provided feedback. Consequently, we are confident that this study carries minimal risk while offering reasonable benefits.

Privacy & Confidentiality

Privacy refers to the right of individuals to control access to their personal information and to determine how that information is used and shared. Confidentiality refers to the duty of individuals or organizations entrusted with this private information to protect it from unauthorized access, use, or disclosure. These are important to maintain trust and to ensure that participants are protected from harmful use of their personal data (Canada, 2022).

To uphold these principles, all notes and written interviews will be securely stored in a locked cabinet within the main researcher's office, with digital copies safeguarded on team computers that require password access. Participants' identities will be anonymized using code numbers (e.g., participant 1) in recordings and papers, affording them an added layer of confidentiality. Additionally, participants have the right to request copies of their notes or interviews and to notify the research team of any inaccuracies for prompt correction.

In instances where pictures or videos are utilized, identifiable information such as faces, and station names will be blurred in the final report to safeguard participants' and others' identities.

While every effort will be made to maintain confidentiality, it's important to acknowledge situations where disclosure may be necessary by law, such as cases involving child abuse, imminent harm to an individual, or certain forms of mistreatment. Despite these exceptions, we are committed to ensuring the privacy of all participants.

Following the conclusion of the research, all data will be securely retained for two years in a locked cabinet, after which digital information will be permanently deleted and disk re-imaging will be performed where appropriate. Physical information will also be disposed of securely shredded to ensure continued confidentiality and privacy protection. Until the disposal of raw data, stringent security measures, including locked cabinets and password-protected computers, will be implemented to safeguard participants' information.

Knowledge Translation

A tool for change:

There is often a long delay between knowledge synthesis and implementation. In health research it is estimated that it can take up to 17 years for health research to be translated into day-to-day practices (Dew & Boydell, 2017). As such, knowledge translation strategies, aimed at bridging this gap, have become increasingly important for researchers concerned with social change.

Originally developed in medicine to respond to gaps between clinical practice and best practices / scientific evidence, knowledge translation (KT) is “a dynamic and iterative process that includes the synthesis, dissemination, exchange, and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthened the healthcare system (CIHR, 2015)”. KT strategies can vary greatly, depending on the audience, goals, and research. For example, these can include video, theatre, visual arts, presentations, policy briefs, and much more (CIHR, 2015).

Knowledge Translation Strategy:

Recognizing the critical role of disseminating research findings in driving tangible change, I am dedicated to effective knowledge translation strategies. To achieve this objective, I propose crafting diverse research products tailored to various stakeholders, enhancing accessibility and usability of the results. By engaging decision-makers, members of the Autism community, and other stakeholders, we can foster collaboration, knowledge exchange, and ongoing advancements in the field.

In addition to the effectiveness of knowledge dissemination and diffusion, Autistic individuals and researchers suggest a mixed approach to delivering findings. Many participants and members of the Autism community have expressed a desire to read about research findings and to learn about themselves or their loved ones (Gowen et al., 2020). However, research is often unavailable, irrelevant, or incomprehensible. Therefore, following a participatory approach, researchers should ensure that the study findings can be communicated in lay terms, published open access journals, presented using a variety of media (videos, infographics, etc.), and sent using different methods (website, social media, email, or by phone) (Nicolaidis et al., 2019; Fletcher-Watson et al. 2019; Gowen et al., 2020; Cascio et al., 2020; Pickard et al., 2022).

As such, I plan to co-create research products with participants shaped by their interests, needs, and strengths. These could range from an online gallery of their photos to short videos or reports. With the participants' consent, I aim to widely share these products through social media platforms, our research website, and presentations at conferences. As mentioned above, it is imperative that participants decide how findings are disseminated to minimize stigma and harm. They should have control over the method and the content, while being recognized for their work.

Furthermore, I plan to publish the findings in academic journals relevant to transportation, urban planning, or healthcare, and present them at conferences, including one hosted by Mobilizing Justice through their Case Studies Grant in the summer of 2026. Additionally, I intend to develop a policy brief, endorsed by the Autism Alliance of Canada. These publications are important for furthering academic research and for making meaningful change in the transportation industry.

To ensure widespread accessibility, I will conduct accessibility audits using Easy Surf and leverage Quoi Media to disseminate research products as op-eds, reaching broader public audiences. Through these initiatives, I aim to maximize the impact and reach of our research, ensuring that community members, industry partners, and governmental decision makers have access to the findings leading to positive change in both policy and practice.

Figure 5: Knowledge Translation Strategy:

KNOWLEDGE TRANSLATION STRATEGY

	CO-CREATION OF RESEARCH PRODUCTS	JOURNAL ARTICLE	PRESENTATIONS	POLICY BRIEF	SOCIAL MEDIA POSTS & OP-EDS
Audience	AUTISM COMMUNITY & GENERAL PUBLIC	ACADEMIC RESEARCHERS	ACADEMIC RESEARCHERS & INDUSTRY PARTNERS	GOVERNMENTAL DECISION MAKERS	AUTISM COMMUNITY & GENERAL PUBLIC
Goal	DISSEMINATION	DIFFUSION	DIFFUSION	DISEMINATION	DIFFUSION

Progress & Timeline:

At this time, I have completed the scoping review and have prepared to complete the research project above. Specifically, I have had critical discussions with the Autism Alliance of Canada (AAC), industry partners, and advisors, validating materials and completing the Research Ethics Board (REB) process. Together we have secured funding and are now planning to begin recruitment and our interviews. We hope to complete interviews and start analysis of the interviews by July 2024, allowing us to begin development of research products.

Figure 6: Research Timeline

RESEARCH TIMELINE

1 **SCOPING REVIEW** — Completed between January & June 2022 ✓

2 **DEVELOPMENT OF RESEARCH MATERIALS** — Completed between June & March 2023 ✓

3 **CONSULTATION WITH INDUSTRY PARTNERS** — Completed between September & December 2023 ✓

4 **FUNDING** — Received January 2024 ✓

5 **RECRUITMENT, INTERVIEWS, & ANALYSIS** — Planned to occur between May & July 2024

6 **RESEARCH PRODUCTS** — Planned between August & October 2024

Limitations

Limitations of Scoping Review

The scoping review conducted for this research presents several inherent limitations. Firstly, the review was constrained by language, as only English-language literature was included. This restriction led to the omission of relevant studies published in other languages or countries. Furthermore, the choice to focus solely on Autistic individuals and their families restricted the exploration of parallels across various neurodivergent communities, thereby obscuring potential shared experiences or disparities. Additionally, the heterogeneity and representation of the samples of these studies remains unclear if all areas of the spectrum were addressed. Like most research done with Autistic individuals, there may have been an over representation of those with low support needs and who have completed secondary education. The absence of intersectionality within the reviewed literature is another significant limitation, particularly considering the disproportionate reliance on public transportation among BIPOC individuals and those of lower socioeconomic status (SES), who may encounter additional barriers to mobility. Lastly, the scoping review was concluded two years prior to the publication of this MRP, potentially overlooking recent developments in the field that could have impacted the findings.

Anticipated Limitations of Proposed Qualitative Study

Anticipated limitations of the proposed qualitative study include potential challenges related to funding constraints and university bureaucracy, which may limit the scope, scale, and timing of the research. The study is geographically confined to a single city, which restricts the generalizability of findings to other Canadian cities contexts. Next, there is a risk of failing to adequately investigate the transportation challenges faced by individuals with autism and other limitations, like physical disabilities, resulting in incomplete or skewed insights into their experiences. The exclusion of individuals with higher support needs poses another limitation, as their perspectives and experiences may differ significantly from those with lower support needs. Moreover, the depth and breadth of interviews conducted may be constrained by time and resource limitations, potentially limiting the richness and diversity of data collected. Lastly, barriers to participation, particularly for individuals of lower income, like the need to have access to a computer and smart phone may contribute to sampling biases, thereby limiting the representativeness of the study findings.

Conclusions

Transportation serves as a vital lifeline, facilitating access to essential services, fostering social connections, and opening doors to employment, education, and leisure opportunities. However, despite its undeniable importance, transportation access remains unequal, with certain groups facing significant barriers to mobility and inclusion. This scoping review sheds light on the specific challenges encountered by Autistic individuals within the realm of transportation

The literature synthesized in this review underscores a pervasive pattern of difficulties experienced by Autistic individuals across various modes of transportation. From navigating crowded subway stations to coping with sensory overload on public buses, the challenges are multifaceted and can impact every aspect of the transportation experience. Despite the growing recognition of these issues, the literature reveals a notable gap in qualitative studies soliciting the perspectives and experiences of Autistic individuals themselves, particularly within the Canadian context.

Considering the lack of data and development of the National Autism Strategy, the proposal for a two-part qualitative study focusing on Autistic young adults in Toronto emerges as a promising course of action. By employing a participatory approach that prioritizes the voices and insights of neurodivergent individuals, this study aims to provide a deeper understanding of their transportation needs, challenges, and aspirations. Through meaningful engagement with participants, community organizations, and policymakers, the study seeks to inform the development of targeted interventions and policy recommendations that promote transportation equity and accessibility.

Statement of Contributions + Conflicts of Interest:

While this research is a requirement to complete my master's degree, the writer does not stand to benefit personally (financially or otherwise) from this work or from the partnerships that are formed. Moreover, his experiences and positionality on the subject as an individual with neurodiverse family members and as a medical professional who works with this clientele will be declared to the participants during the activities and within the final write up.

Next, although industry partners have been solicited to provide their input on the appropriateness of questions and materials, they will have been excluded from recruitment, data collection, and analysis. As such, they should not have had any influence on the responses of others.

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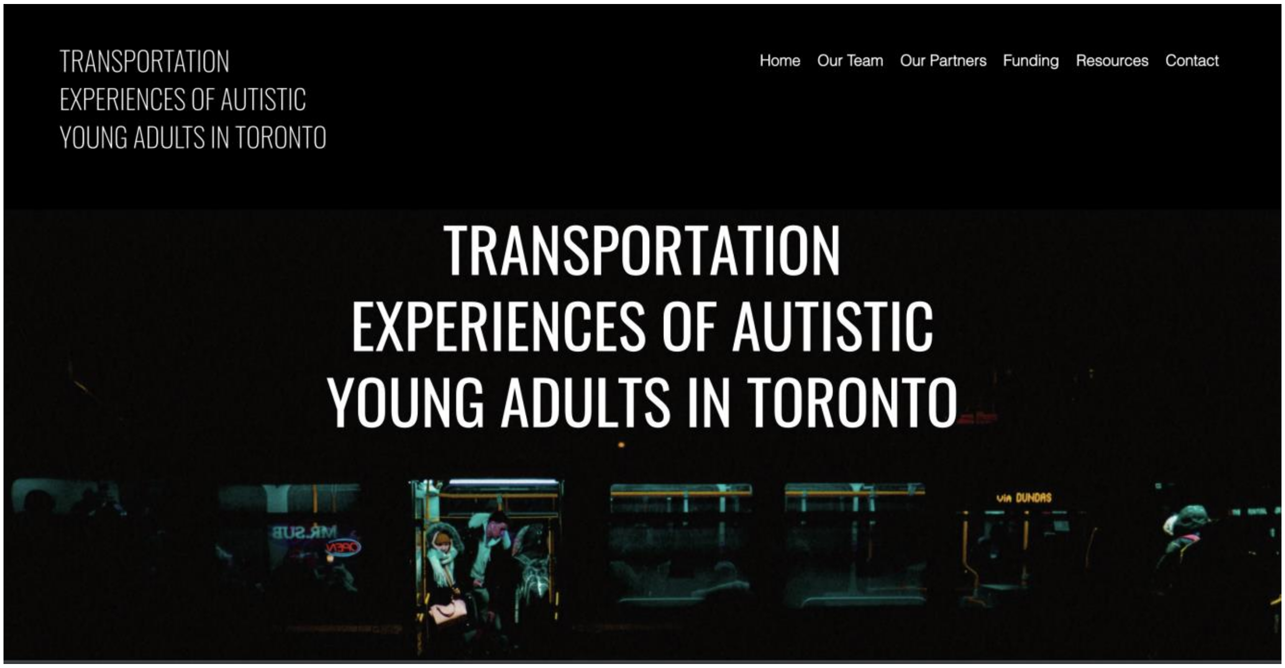
Appendix

PLEASE NOTE: The PRISMA table, journey map, consent forms, demographic questionnaire, and other supporting documents have been submitted as supplementary documents.

Appendix 1: Recruitment Materials (Website)

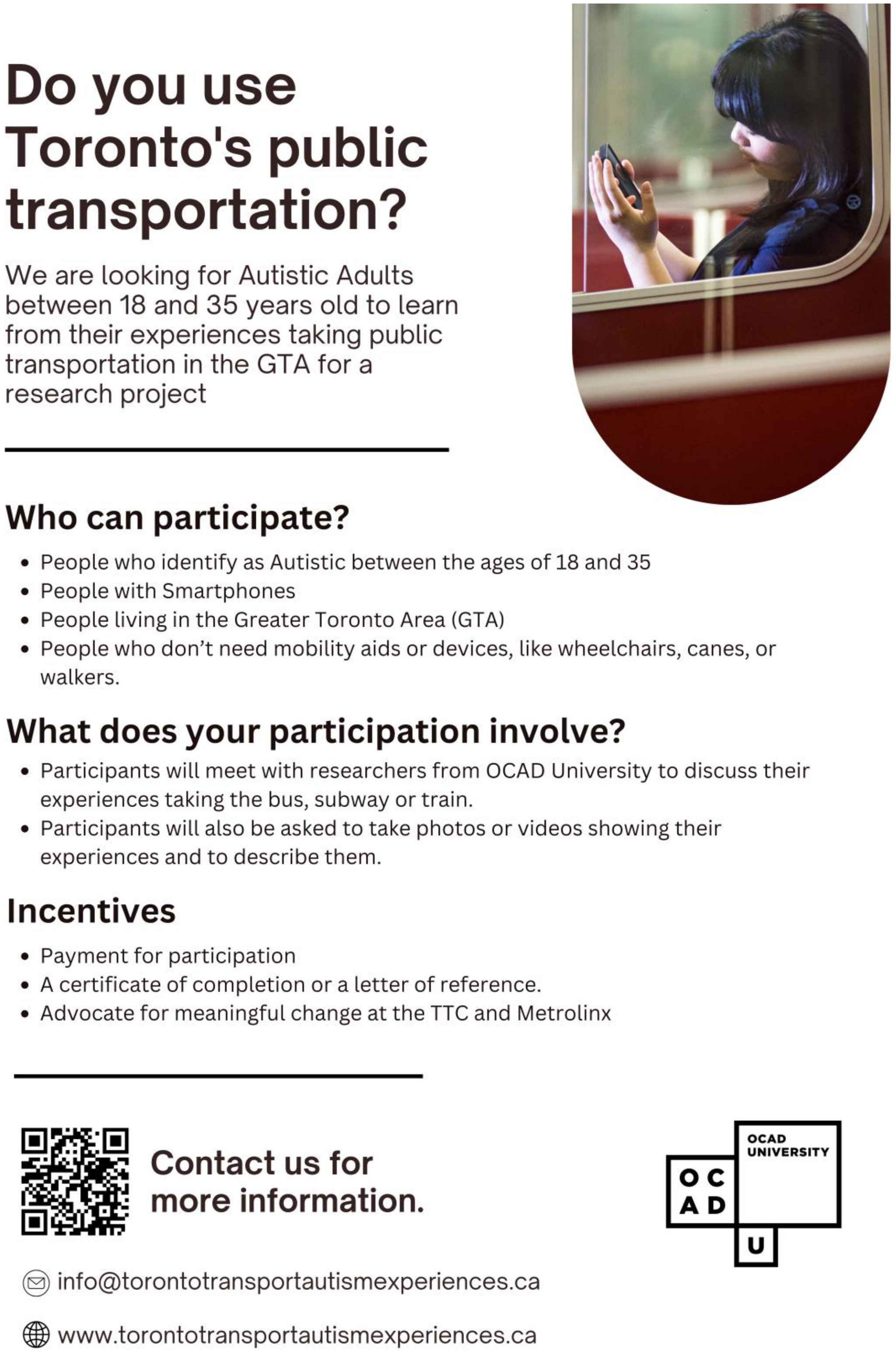
https://www.torontotransportautismexperiences.ca/



TRANSPORTATION
EXPERIENCES OF AUTISTIC
YOUNG ADULTS IN TORONTO

TRANSPORTATION
EXPERIENCES OF AUTISTIC
YOUNG ADULTS IN TORONTO

Appendix 2: Recruitment Materials (Poster)



Do you use Toronto's public transportation?

We are looking for Autistic Adults between 18 and 35 years old to learn from their experiences taking public transportation in the GTA for a research project

Who can participate?

- People who identify as Autistic between the ages of 18 and 35
- People with Smartphones
- People living in the Greater Toronto Area (GTA)
- People who don’t need mobility aids or devices, like wheelchairs, canes, or walkers.

What does your participation involve?

- Participants will meet with researchers from OCAD University to discuss their experiences taking the bus, subway or train.
- Participants will also be asked to take photos or videos showing their experiences and to describe them.

Incentives

- Payment for participation
- A certificate of completion or a letter of reference.
- Advocate for meaningful change at the TTC and Metrolinx

Contact us for more information.

OCAD UNIVERSITY

info@torontotransportautismexperiences.ca

www.torontotransportautismexperiences.ca

Appendix 3: Interview Questions

The following questions have been prepared for review by the advisory committee. We recognize that we will not be able to ask all the following questions, but we have prepared the following to account for various responses. We will likely be able to ask between 6 and 12 questions, depending on the participant.

Introductory Questions:

- What does a typical route/ ride look like? What mode of transportation do you use?
- Where do you take public transportation?
- Do you take the same route? Does your route change?
- How often do you take public transit?
- Are you taking public transit alone? / With whom are you taking public transit?

Planning/ Leaving the home:

- What is involved in planning your trip?
- How do you get to the bus/train/subway stop?

Waiting for Transportation:

- What is your experience waiting for the public transit? (How long do you typically wait, what features do you like (e.g. seating, shelter, etc.), what do you do)?

Purchasing a Ticket:

- Can you describe your usual process for buying a transit fare in Toronto?

Follow up questions:

- Do you prefer using specific methods like kiosks, mobile apps, or ticket booths?
- Are there any challenges you've encountered while purchasing a transit fare? This could be related to understanding pricing, navigating the options, or any difficulties with the machines.
- Are there any suggestions you have to make it a smoother experience?

The Ride:

General Questions:

- What is something that you find challenging or difficult when you ride public transit?
- What is something that you like about your ride?
- What is something that you enjoy about your commute?
- Do you do anything or use any supports to make your ride more enjoyable?
- What is something that you would change about your commute?

The following are anticipated follow up questions based on the literature and that can be used depending on participants' responses.

Follow up questions general

Way Finding:

- How do you make sure that you are going in the right direction or getting off at the right time?
- How do you figure out where to go and find your way around?
- Have you ever felt lost or unsure about directions? What do you do to help you find your way?
- What tools or strategies do you use to help you navigate unfamiliar places, like maps, signs, or asking for help?

Sensory Experience:

- What do you notice about the sounds, sights, and smells around you during your daily commute? Do they impact your ride?
- Do certain sensory experiences, like loud noises or bright lights, affect how you feel during your journey?
- How do you cope with sensory experiences that might be uncomfortable or overwhelming during your commute?
- Are there any sensory aspects that you particularly enjoy or find calming during your travels?

Social Environment

- Please describe some experiences you've had while interacting with fellow passengers during your rides
- Have you ever encountered any challenges or uncomfortable situations when dealing with others on public transit? How did you handle them?
- Do you usually interact with other people while using public transportation?

Physical Environment

- Is there something in the physical environment that you find helpful or harmful? (e.g. cleanliness, physical access, etc.)

Unexpected Events/Safety:

- Do you feel safe when taking public transportation? What makes you feel safe? What does not?
- Has something unexpected happened while you have taken public transportation? If so, what happened?
- How do you handle situations where there might be unexpected changes or delays that affect your arrival at your destination? Is there something that you have found helpful?
- What can transportation providers do to environment to help you feel safer?
- Is there something transportation providers can do to help you feel safer or more comfortable when unexpected events or disruptions happen?

Arriving:

- How do you make sure you get to your destination?

- What steps do you usually take to make sure you get off at the right stop or station when using public transportation? Do you have any tools or strategies?
- How do you feel after the ride when you arrive at your destination?

Learning to take public transit:

- When and how did you start taking public transit? How did you learn? Did anyone help you?
- If you were to help someone else learn how to use public transit, what advice or tips would you give them to make the process smoother?
- What resources or methods did you find most helpful when you were figuring out how to navigate the public transportation system?
- Did you have any challenges or concerns when you were learning to use public transit for the first time? How did you overcome them?
- How confident do you feel now about using public transit compared to when you were just starting to learn? What contributed to your growing confidence?

Opportunities for co-design / Accessibility Services

- How would you like transit agencies (TTC and Metrolinx) to go about getting advisory feedback?
- How would you like to be involved in making changes to transit?
- Do you use or are aware of any of the accessible and safety features offered by the TTC and Metrolinx (e.g. wheel-trans, transit training, Safe TTC App, etc.)

Appendix 4: Photo-Voice Prompts

Take pictures of things that catch your attention or that best reflect your journey. To help guide your photos, think of these questions:

- What is involved in planning your trip? How do you get organized?
- What do you do when waiting for the bus/train/tram/subway?
- What is something that you find challenging or difficult when you ride public transit?
- What is something that makes your ride easier or more enjoyable?
- What is something that you enjoy about your commute?
- What is something that you would change about your commute?
- What would you do to change the public transit system to improve your experience?

IMPORTANT: Please be safe when taking photos. Do not go places that you would not normally go to or where you could get hurt. Please stay on the platform and in designated waiting areas.

Also, keep in mind that if you take someone's pictures without asking them first, it might invade their privacy. While it is unlikely, some people might get upset if you take their picture without permission. So, it's important to be careful and consider how to do it nicely. Also, instead of taking pictures of others, you can take photos or videos of objects/environments or of yourself.