**Autism**
Alliance of Canada

Alliance canadienne de
**l’autisme**

# Autistic Adults in Focus: Understanding Mental Health and Social Support Needs and Barriers

## Phase 2 of the Canadian Autistic Adult ~~Needs~~ Assessment Project

**Public Report**

October 2024

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McMaster University

Sinneave Family Foundation

# Acknowledgements

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## Research & Knowledge Translation Support

Simone Daniels, Research Assistant, Autism Alliance of Canada

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# Preface

## Autism Alliance of Canada

Autism Alliance of Canada is a non-profit organization that comprises a diverse membership, including Autistic people, caregivers, clinicians, researchers, policymakers, and autism organizations across Canada. United as a shared leadership movement, we are committed to advancing autism research and policy, advancing equal rights and opportunities for Autistic people in Canadian society.

Our research focuses on systems and policies, addressing the priorities of our members across different research and policy domains. Working closely with the government, we integrate lived experiences with national expertise to effectively shape policies that can support Autistic people and their families. Promoting meaningful inclusion, we engage Autistic people in leading projects, participating in initiatives, providing policy briefings to senior-level officials, contributing to research and priority-setting, and supporting Autistic scientists and trainees to lead impactful initiatives in research and policy.

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## Preface

# Language and Terminology

## Language Statement

How we use words is powerful and shapes how we see the world. It also affects how we see ourselves and others. People have different opinions about how we should talk about autism. Some say we should use person-first language, like saying “person with autism.” Others prefer identity-first language, such as “Autistic person.”

More and more, research and writings from the community show that many Autistic people don’t like person-first language. They think it might make the stigma (negative views) around autism worse. Identity-first language says that being Autistic is a big part of who a person is. This way of talking is also used and accepted by the Blind and Deaf communities.

After looking at the research and hearing from Autistic members of Autism Alliance of Canada, we’ve chosen to use identity-first language in this report. This is in line with the language guide Autism Alliance of Canada published, based on community input, available here: https://autismalliance.ca/resource/language-guide/

# What To Know Before Reading This Report

## Points of View

This report presents the data and results from the Canadian Autistic Adult Needs Assessment Project. The interpretations and suggestions included are from the authors, relying on the focus group results and their knowledge and experience detailed above.

## Quotes

This report contains quotes from the focus group participants. We didn't change the content in their responses, keeping them as they were stated, however, we did shorten quotes where needed for brevity and clarity. In cases where someone could be identified from a quote, the identifying information was removed or changed. All quotes are attributed to their speaker by the type of group they participated in and their age.

The quotes are set apart from the main text with quotation marks.

# Executive Summary

## Why we did this work

Autism Alliance of Canada was tasked by the Public Health Agency of Canada (PHAC) with the conduct of a national needs assessment survey among Autistic adults: "Fostering Inclusion: Exploring the Needs of Autistic Adults in Canada. An Autistic-led Survey". That project sought to explore the needs of Autistic adults in Canada and explored various domains including physical and mental health, transportation, housing, employment, finances, and access to healthcare and social services.

**Respondents to that survey identified mental health and social connection support as the two main priority areas for researchers to further investigate.** Thus, the Autism Alliance Research Team partnered with Sinneave Family Foundation and McMaster University to develop Phase 2 of the Autistic Adult Needs Project. The goal of Phase 2 was to hear first-hand from Autistic adults in Canada via focus groups to further explore the identified priority areas as they related to service needs and barriers to accessing existing services.

This report presents the results from Phase 2, including the mental health and community-based social support needs and access barriers among this population. Further, the findings from this report include a set of recommendations synthesized from those put forth by our participants that serve as a starting point to addressing the complex mental health and social connection needs of Autistic adults in Canada.

## What we did

This project consisted of 12 facilitated, virtual, focus group discussions involving 64 Autistic adults living in Canada. In these discussions we sought to learn about the mental health and community-based social support services and supports that Autistic adults in Canada lack. We also explored the access barriers to existing services and supports, and collectively developed recommendations for actions that could help address these issues. Focus groups were chosen as the approach for this project to ensure that Autistic people could explain in detail what their service needs and barriers to accessing services were in their own words.

The focus groups were led by professional facilitators, with the research team observing. Participants received materials and the focus group questions ahead of time to prepare. The focus groups were run using a modified Nominal Group Technique paradigm. These groups were subdivided by gender identity, with 4 groups for cisgender women, 4 groups for cisgender men, and 4 groups for gender-diverse people.

# Language and Terminology

## Our Sample

The focus groups for this study included 64 participants, with approximately 70% of them being between 30 and 45 years old and with diverse representation across gender identities. Autistic adults from eight provinces across Canada participated. Almost two-thirds of participants had a formal diagnosis of autism, while just over one-third of respondents self-identified as Autistic. Participants were evenly distributed among gender-stratified groups, with notable representation from gender-diverse people. Geographically, the sample was predominantly from Ontario and British Columbia. The participant group was highly educated, predominantly English-speaking, and mostly White, with a small proportion identifying as having multiple ethnicities. Notably, the study did not reach people who speak only French or non-speaking participants, highlighting areas for future research to ensure broader inclusivity and an accurate representation of the levels of need of the Autistic community. While it is evident that Autistic adults face significant needs and are underserved within the system, it is important to note that the reported results probably underestimate the actual level of need, which may be much higher due to the characteristics of the study sample.

## Key Findings

Our findings highlight significant gaps and barriers in mental health and community-based social services for Autistic adults in Canada. These findings will likely not be new to people working in the autism services sector or who have lived experiences of autism in Canada, but what makes these findings important is that they are from the experiences Autistic adults themselves. When looking at systems and services from a high level, it may be easy to miss the experiences of service delivery at the local or individual level. This report exemplifies those experiences.

The gaps and barriers identified in this report include a shortage of adult-focused mental health care, insufficient access to autism-competent practitioners, and inadequate diagnostic services. Autistic people face substantial challenges in accessing essential services, exacerbated by long wait times, administrative hurdles, and a lack of affordable options, especially in rural areas. Social support systems also fall short, with a lack of community-based programs, insufficient employment and daily living supports, and limited Autistic-led initiatives. Further, societal awareness and acceptance remain inadequate, with those with intersecting identities facing additional challenges.

This report also presents recommendations synthesized from the input of Autistic adults to improve services and decrease barriers to access. Those recommendations were augmented by the Autism Alliance policy and research team to propose concrete actions that could be undertaken by Autistics, service providers, governments, researchers and civil society organisations. These actions will start to fill gaps in services and their delivery, accessibility, and societal inclusion to meet the diverse needs of Autistic adults.

# The Report

# 1 | Introduction

In Canada, approximately 1 in 50 children and youth have been diagnosed as Autistic, which equates to roughly 2% Canadian children and youth.[1] As of the release of this report, there are no precise estimates specific to how many Autistic adults live in Canada. The lack of information regarding the adult autistic population emphasizes the importance of this work. Autistic children grow up to be Autistic adults and the needs people have can change over one's lifespan.

Autistic people often face systemic challenges and a lack of understanding from society, particularly concerning the nuances of their experiences and needs.[2] This has led to an overlooked and underserved population, especially among Autistic adults who have been historically excluded from research, which has instead focused primarily on children.[3–6]

Autistic adults, especially those with invisible disabilities and co-occurring conditions, often struggle with accessing adequate mental health and social support services.[7,8] Canadian society at large may not fully recognize the shortcomings of the current support systems, which are often discriminatory and inadequate for addressing the complex needs of Autistic people.[9,10]

Autism Alliance of Canada conducted a national needs assessment survey for Autistic adults aged over 30, which identified substantial gaps in service provision and support for Autistic adults in Canada.[11] The few other Canadian studies in this area also support these important findings.[7,12]

While recent advancements in the research landscape have started to investigate these issues,[13] there still remains a significant gap in understanding the diverse needs of Autistic adults.[14] Most current research looks at 'optimal' outcomes decided by non-Autistic researchers and physicians, but it often doesn't cover the range of experiences of Autistic people.[15]

This project sought to advance qualitative participatory research that centers Autistic people, particularly those over the age of 30, providing a platform for their voices to be heard and considered in decision making. Autism Alliance of Canada's mission underscores the importance of including Autistic voices in these conversations. This work directly addresses a community ask for increased research focus on mental health and social connection in the Autistic community; these areas were identified as priorities in the national needs assessment survey conducted by our organization.[11]

The findings of this study may not be surprising to those deeply embedded in the Autism services sector, yet they remain critical. There is a common misconception that the Autistic experience is well understood when, in reality, most people have not heard directly from Autistic people about their experiences. The saying 'When you meet one Autistic person, you meet one Autistic person' emphasizes the diversity within the community and the importance of hearing first hand from those with lived experience.

In this study, we heard from Autistic adults themselves about their individual experiences. There is a great deal of nuance, power, and importance in listening to people with lived experience talking about their needs, and the barriers they face, in the ways that are most meaningful to them, that can be missed when one talks about mental health or community-based social support services programs more broadly.

This study is one of the largest qualitative studies focused on health service needs in Autistic adults in Canada.[7,10,16] This report, which relays study findings, serves as a foundational step toward informing decision-making processes for various stakeholders, including policymakers, service providers, and the broader community. By providing insights into the needs of Autistic Canadians, it aims to lay the groundwork for developing more effective and inclusive support systems. While this initial research is crucial, ongoing efforts and further studies will be essential to refine these insights and ensure that the needs of Autistic people are fully addressed in future policy and practice.

## Study Aim

To identify the mental health and community-based social services needed by Autistic adults in Canada, understand their barriers to access, and gather community-driven recommendations directly from Autistic adults to improve support and service delivery.

## Research Questions

1. What types of mental health supports do Autistic adults in Canada need?
2. What types of community social supports do Autistic adults in Canada need?
3. What are the current access barriers to needed supports in the mental health and community social support spheres?
4. What are community recommendations for helping address the identified needs?

# 2 | What we did: Focus groups

## Methods Overview

This study gathered the perspectives from 64 Autistic adults across Canada via 12 online focus groups. These lasted approximately 2 hours each and were led by professional facilitators with support from the research team members, who were present at all sessions as observers. The research team conducted all data analysis and reporting.

## Recruitment

Participants were recruited based on their participation in the Canadian Autistic Adult Needs Assessment Survey. Emails were sent out to everyone who participated in the Survey and who consented to be contacted about future research. A series of time slots were set up ahead of time taking into account the availability of the facilitators, the research team, as well as trying to provide a variety of dates and times to accommodate different time zones. People who responded, and were available to participate, indicated which time slots they were eligible for, as well as which type of gender group they would prefer to participate in. This information was added to a waitlist on a first come, first served basis, per time slot, and was used to form the focus groups.

Further, the focus groups required at least some verbal participation. Given that the groups were hosted online, the text/chat box was an option for some of the activities, however people who are non-speaking would not have been able to participate in all activities. Those who have situational mutism were able to join and offer contributions both verbally and through the chat. All focus groups were conducted in English due to not having enough participants in any one group type or timeslot to run any French-language groups.

Participants were offered compensation for their involvement in the focus groups, acknowledging the importance of reimbursing people for their time. Compensation was optional, at the participant’s discretion, as receiving financial compensation could have negative implications for those receiving disability benefits.

# 2 | What we did: Focus groups Cont'd

## Data Collection

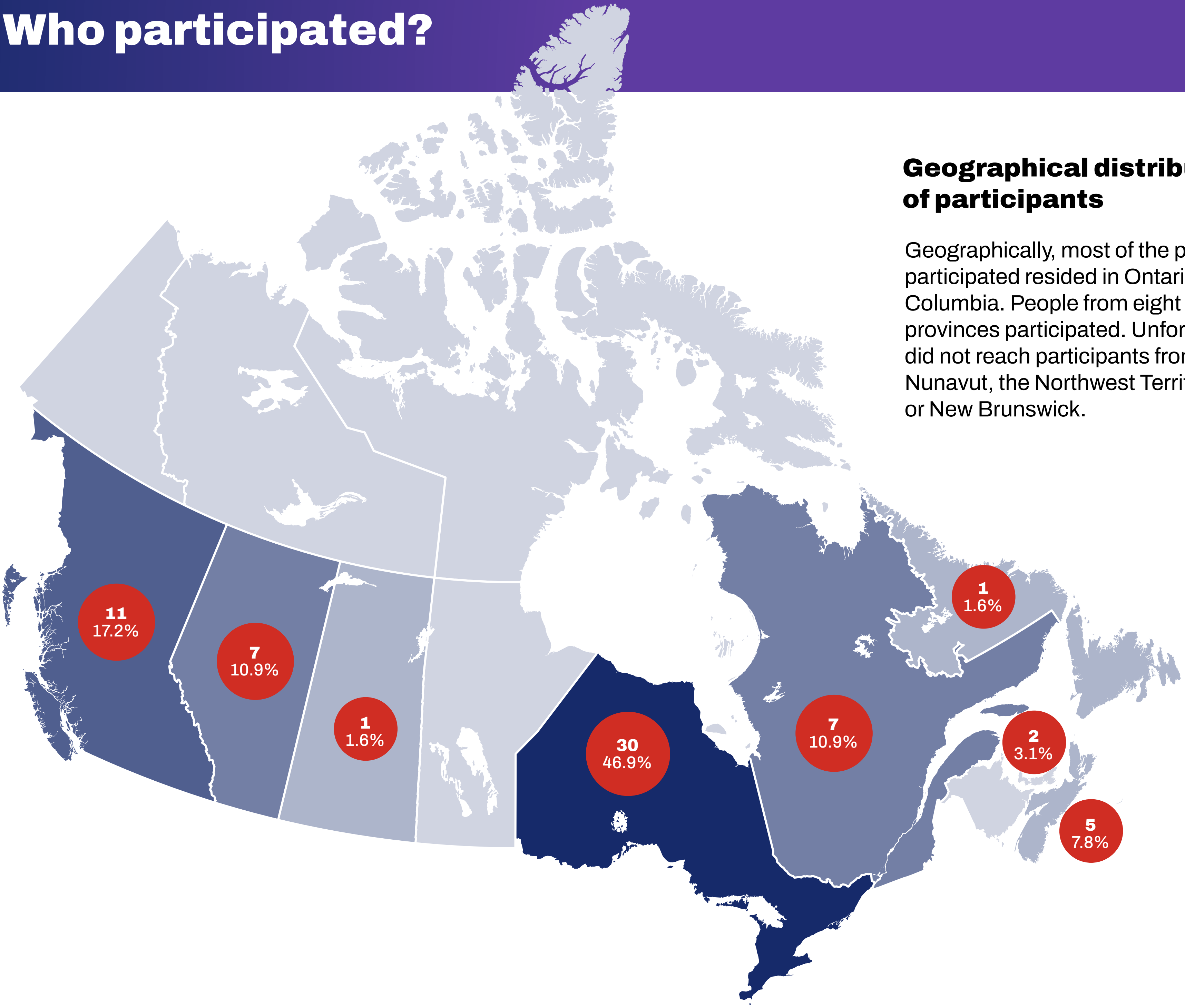
We ran 12 focus groups stratified by gender: 4 focus groups each for cisgender men, cisgender women, and gender diverse people, with the intent of achieving saturation.[17] A total of 64 people participated across the 12 focus groups. The gender stratification was implemented to ensure participant comfort, recognizing that people might feel more at ease discussing personal experiences in groups composed of others with similar gender experiences. Participants chose which type of group they wished to participate in.

The focus groups were administered over Zoom and were recorded for analysis and subsequently transcribed and reviewed.

We employed a modified nominal group technique (NGT) approach[18], where we shared results from the first phase of this project[11] with participants for them to reflect on. We then provided a worksheet (see Appendix A in this report) with our research questions and prompts to allow participants to reflect and generate ideas before the focus group session. The outcomes from the focus groups were a comprehensive list of service needs and access barriers to both mental health and community-based social supports among the sample of Autistic adults. Participants also collectively produced a list of recommendations that they felt would help ameliorate these concerns.

What we did: Focus groups

# Who participated?



## Geographical distribution of participants

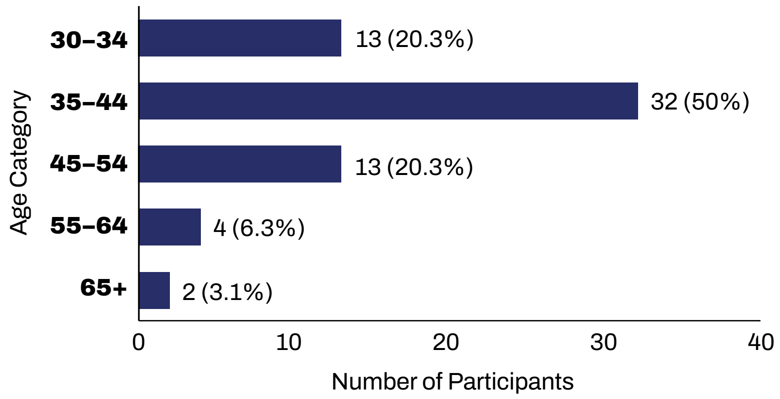
Geographically, most of the people who participated resided in Ontario and British Columbia. People from eight different provinces participated. Unfortunately, we did not reach participants from the Yukon, Nunavut, the Northwest Territories, Manitoba, or New Brunswick.

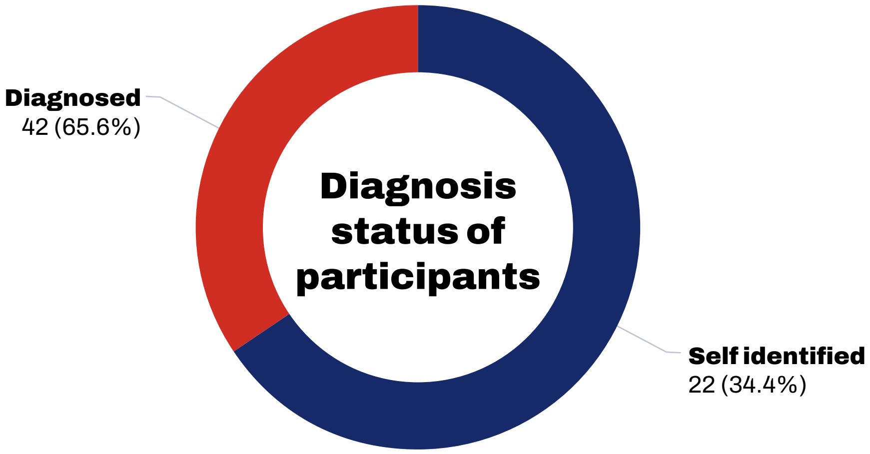
### What we did: Focus groups

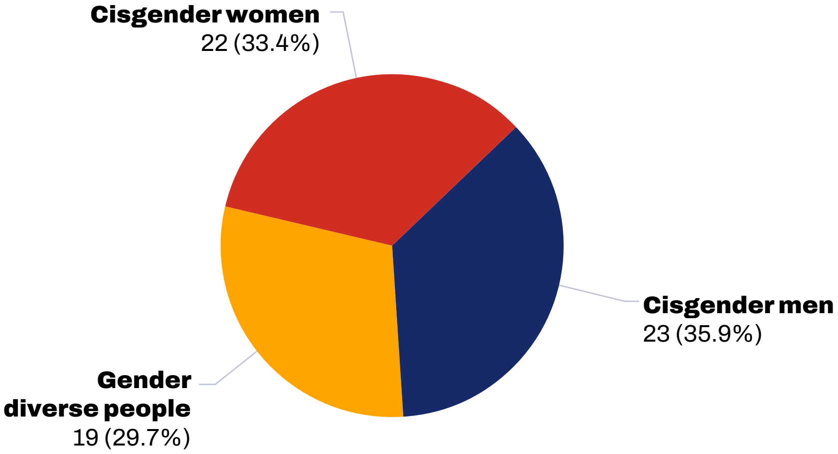
# **Who participated?** Cont’d

Of the 64 focus group participants, the majority (70.3%) were younger than 45 years old and 9.4% were 55 years of older. Regarding diagnostic status, nearly two thirds of participants had a formal diagnosis, and about one third self-identified as Autistic.

## Age of participants





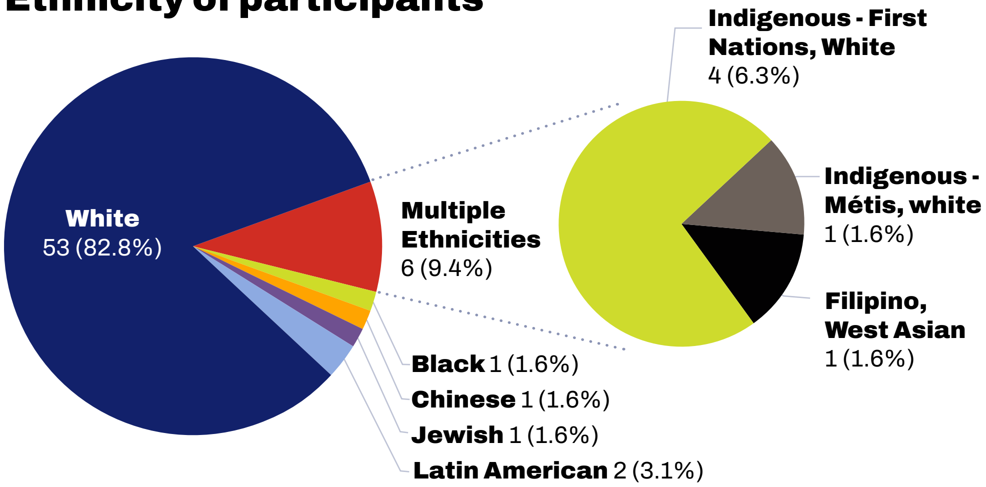


## Participants per gender group

As discussed above, participants chose which type of focus group they were comfortable participating in and the groups were stratified by gender. We had a fairly even split between all groups. The gender diverse focus group included people who identified as transgender, non-binary, two-spirit, and neurogender.

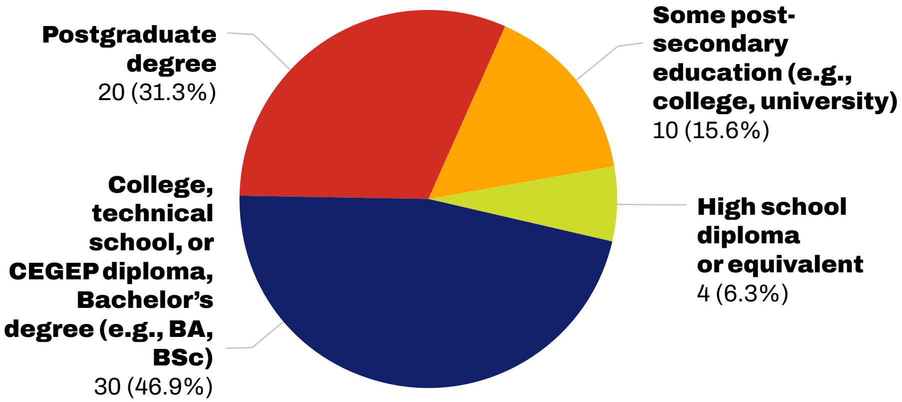
# Who participated? Cont'd

## Ethnicity of participants



The vast majority of participants were White, and 9.4% of participants indicated they have multiple ethnicities. Of the participants who indicated that they have multiple ethnicities, 7.9% of participants identified themselves as Indigenous.

## Level of education completed by participants



This group of participants was highly educated with 78.2% of participants having completed any level of post-secondary education.

Over 90% of participants indicated that they were comfortable participating in English, and 7.8% indicated they were comfortable participating in either English or French. Further, 1.6% of participants indicated they were comfortable participating only in French, however they chose to participate in English.

## Who was missing?

Since the participants were drawn from the Canadian Autistic Adult Needs Assessment Survey, the limitations of that study also apply here. We had a predominantly White and highly educated sample with lower levels of support needs in that survey. For more details on those limitations, please refer to the original report. Additionally, although we intended to offer focus groups in French, there was insufficient interest from participants to proceed with them. Nevertheless, bilingual people and residents of Quebec were included in the focus groups. The current focus group design did not accommodate non-speaking people; however, text chat was available for use by people who have situational mutism. Future studies will aim to include these groups to better understand their experiences.

# 3 | What we found: Needs and Barriers

In the focus groups, participants provided insights into both their mental health and community-based social support 'needs' — what services and supports they require to better manage their wellbeing and daily lives — and the challenges they face in accessing these services — referred to as 'barriers'. We carefully analyzed these insights to identify recurring patterns and issues. These patterns were then organized into broad themes, which are outlined below. This approach helps us to understand the specific needs of the community and the obstacles they encountered.

## Priority Area: Mental Health

### 3.1 Mental Health Service and Support Needs

### 3.1.1 Types and scope of mental health service/supports

Participants in the focus groups discussed different types of services they needed for their mental health along with how they use services.

***Lack of Adult-Focused Care:*** There is a distinct need for adult-focused mental health and autism services, including services that employ a life-course perspective to address unique mental health needs while aging.

> **"I mean people who are over 18... Once you've already passed this magical age where you've aged out of the child care system, it's kind of like you're like, okay, we're done with you. And you're asking people to, you know, give you supports, but they're kind of like, well, you're not a child, so what do you want from me?"**
>
> —Gender diverse group participant, 37 years old

> **"There's nothing really extraordinary about me. I'm just here because I think that there's zero... there's next to zero research on Autistic adults and what their needs are, because apparently autism ends when you're 18 and the needs of an Autistic five year old are the same as the needs for an Autistic 46 year old apparently within society. So I'm glad that Autistic adult research is being done so that that could be debunked."**
>
> — Women's group participant, 47 years old

# 3 | What we found: Needs and Barriers Cont'd

***Insufficient Capacity in Existing Service Offerings:*** There is a general lack of capacity in the system to take on new patients/clients, or be able to see patients/clients as frequently as they need. Participants described wanting to have regular and reliable access to mental health care providers.

***Limited types of treatment options:*** Participants stressed the need for a variety of treatments to be available for mental health, advocating against a one-size-fits-all approach to services and supports. They specifically mentioned the importance of offering different types of therapy such as dialectical behaviour therapy and somatic therapy in addition to more common types, like cognitive-behavioural therapy.

***Shortfalls in therapy and counseling services:*** There is a specific need for more capacity for patients/clients in therapy, counselling, and coaching services. Many participants mentioned that these types of services were a preferred therapeutic approach for them, though that it was hard to get regular appointments.

***Lack of Group Therapy and Peer Support Groups options:*** There is a need for group therapy and/or peer support group options for Autistic adults. Participants reported that group therapy options with like-minded people can be supportive and help improve their sense of community.

> **“We know when an Autistic person has a positive self-identity and positive social identity, their mental health is also tend to be improved. And in the few Autistic groups I've been a part of creating and founding, either online or in person, just Autistic people seem to really benefit from being in a group where our own social cues, our own style of communication, all of that gets to be celebrated and normalized as opposed to a group where we're trying to learn how to fit in or be normal. And I think it also helps people be more aware of and I think it empowers people to feel stronger in their own advocacy for what they might need in the outside world and to just realize that they're not isolated and their experiences aren't abnormal and that they're their ways of thinking and talking and being are also not abnormal.”**
>
> —Women's group participant, 40 years old

***Inadequate access to medication related therapies:*** There is a need for increased access to medication-related therapies and alternative pharmacological approaches. Participants noted that there is a general lack of knowledge of the paradoxical effects that medications can have on Autistic adults among practitioners and the participants also needed knowledgeable professionals to help them manage their prescriptions. Specific medication therapies that participants noted they needed were addiction, pain-management, hormone and psychedelic therapies.

# 3 | What we found: Needs and Barriers Cont’d

***Insufficient Ancillary Support Coverage and Funding:*** There is a need for increased availability of, and government subsidy/coverage of, ancillary services, those not traditionally covered by provincial/territorial health insurance but that can provide much-needed support, such as occupational therapists, social workers, interpreters, and accountants with specialized knowledge of disability supports including the Disability Tax Credit.

***Lack of Autism-Specific Supports:*** There is a need for more services that consider and accommodate sensory concerns and sensitivities, meltdowns, executive functioning issues, and other traits uniquely common in autism.

> **“There’s often a misconception that sensory barriers are sensory choices. Like, ‘Oh , you don’t like that smell?’ Well, it’s not about not liking that smell. It’s actually causing me physical pain. And it’s not that I’m being picky, it’s that I actually have a disability in which I can’t be here.”**
>
> — Women’s group participant, 40 years old

***Inadequate Support for Broader Mental Health Issues:*** There is a need for increased support with mental health concerns that are not directly related to one’s autism (e.g., depression, anxiety, eating disorders, trauma).

***Insufficient support for Autistic parents:*** Specific supports for Autistic parents are also needed, including accessible and affordable childcare, and family-friendly service providers (such as providers who can treat families together).

### 3.1.2 Mental Health Service Needs Related to Practitioners

Participants noted that they had some needs focused not necessarily around particular treatments and service options, but on the approach their healthcare practitioners take in providing services and the specific expertise of the practitioners.

***Lack of Autism-Competent Practitioners:*** There is a need for practitioners who are competent in autism care and understand what autism is and how it presents, including across intersectional groups (e.g., Autistic women). This need also encompasses an ask for more autism-focused education for providers to increase service quality.

# 3 | What we found: Needs and Barriers Cont'd

> **[I would like to have] counselors that are educated in autism specifically, because there are a lot of people who have like a certain list of things that people should you know, people should fit into certain boxes according to certain people. And not everyone does fit into those boxes. I'm Autistic and I have ADHD and there's a lot of crossover, but there's a lot of differences between both diagnoses and it can make life pretty complicated. So to be able to go to see someone who knows the difference, who knows how to deal with or help you deal with and manage certain symptoms would be excellent."**
>
> — Gender diverse group participant, 38 years old

***Lack of Neurodivergent Practitioners:*** There is a need for more providers who are neurodivergent or Autistic themselves. Participants expressed that there is a unique role for neurodivergent people in treating neurodivergent people, including using their lived experience to inform and enhance the quality of the services they offer.

> **I would like more Autistic people in roles in mental health and social services. I think it is important for the Autistic people to see ourselves. (...) I think having people who understand autism matters, and having a good choice for people who want to go see someone so that they can pick between people [matters too]."**
>
> — Women's group participant, 44 years old

> **I think what would be wonderful is if the government had some sort of subsidized programming to get more neurodivergent counselors and mental health practitioners into the field. So it would address the the need for more care providers while also focusing and specializing on very specific type of care."**
>
> — Women's group participant, 40 years old

***Lack of SGM-Competent Practitioners:*** There is a need for practitioners and services that understand queerness, trans-ness, and overall sexual and gender minority (SGM) intersecting identities.

***Inadequate Neuro-Affirming Care:*** There is a need for more practitioners (and, in turn, services) that accept and value different ways of thinking and learning, and experiencing the world in a neuro-affirming manner. This includes services or supports that take a strengths-based approach and accept the broader neurodiversity and disability movements, not just autism. As an example, one participant mentioned the need for neuro-affirming therapists who could provide couples or marital therapy.

***Insufficient Continuity of Care:*** There is a need for a more integrated person-centred approach to healthcare. Participants spoke of frustrations with having to engage with multiple therapists, retelling their stories and experiences multiple times, as well as not being able to forge ongoing relationships with their practitioners, and practitioners not communicating with each other. The participants also want more individualized care options from a single provider.

### 3.1.3 Diagnostic Services

Lack of Accessible and Affordable Diagnostic Services: There is a need for increased capacity and availability of diagnostic services and autism assessments for adults. These assessments need to be affordable, timely, and easily accessible. Without an assessment and subsequent diagnosis, access to further publicly funded supports and services is limited.

> **"As long as the diagnostics are not equitably available, we have to consider that there's a whole herd of struggling human beings out there that desperately need a place to belong and decompress."**
> — Gender diverse group participant, 38 years old

> **"I have health insurance, I have coverage, they could have paid for most of the cost of the assessment, but they have a list. So it hits barriers with the insurance companies if the person is not registered on their list of providers, they will not cover their fees . So it was hard having to try to find money out of pocket , which happened only because my my father happened to pass away in the middle of all this and I ended up inheriting some little bit of money. And that's , that's how I got my diagnosis, because my I had to lose my father to get my diagnosis."**
> — Women's group participant, 49 years old

### 3.1.4 Social Determinants of Mental Health

Social determinants of health are "non-medical factors that influence health outcomes".[19] The themes below represent needs participants mentioned in the focus groups that are related to social determinants of health and that affect their mental health.

***Insufficient Employment Supports:*** Participants reported a need for increased availability of employment supports, including supports for both finding and keeping jobs. Some participants discussed how employment was one of their only opportunities for social interaction in their everyday lives and not having a job worsened isolation, depression and created further financial pressures and sources of worry.

# 3 | What we found: Needs and Barriers Cont’d

> **I don’t have safe access to my job, which was my source of joy. It was a source of mental balance. I absolutely loved doing it, it was my purpose and all that kind of thing. So that greatly affects my mental health and I’m not even too sure how to get that back other than if society starts adopting protections for immunocompromised and other disabled people. So that’s a huge one on for my mental health support.”**
>
> —Gender diverse group participant, 47 years old

> **I would like to receive more support with regard to getting a job. [...] I find that having a job solves my lonely and loneliness problem. So getting a job helps with my mental health in that sense.”**
>
> —Men’s group participant, 35 years old

***Lack of Supports for Social and Relationship Stresses:*** There is a need for supports to help with navigating interpersonal relationships. This includes assistance with improving social skills, making friends, and managing stress in relationships.

***Insufficient Supports for Daily Living Activities:*** Participants described needing support with daily activities such as preparing food, washing dishes, doing laundry, cleaning, parenting, general caregiving, and general life stresses. Participants described having both limited energy in the day, ‘spoons’, to handle these tasks and a lack of knowledge about what daily life should look like. In particular, some participants indicated a desire to explicitly learn how to do some of these things, including an interest in more financial literacy.

> **[I’d like help with] basic life needs help or just for help cleaning up around the house batch cooking just basic life things that I think a lot of us struggle with. And that’s where I find that if I were just to have a couple hours of support, maybe for batch cooking and for maybe tidying up around the house, I can save probably 10, 15 hours of my own time, and put that towards, you know, a job or something like that or put it to better use and be able to focus on and be a lot more productive on things I’m actually capable of doing.”**
>
> — Men’s group participant, 47 years old

> **"I think it's really important to work on expanding support to the invisible needs. Like if you have a neurodivergent person who can be completely functional in the workplace, but that takes everything and then their house is a mess and they can't keep up with cleaning or anything and they can barely feed themselves, that's not functioning."**
>
> — Gender diverse group participant, 36 years old

***Insufficient Financial Support:*** There is a need for increased financial support to allow people to meet their basic needs (e.g., housing, groceries). The stresses around money and not being able to pay one's bills or having to pay the 'disability tax' (paying more for items or services because you cannot do them the same way as a person without a disability would, such as having to pay a premium to get groceries delivered because you cannot drive due to disability) on necessary goods creates pressures that negatively influence mental health.

### 3.1.5 Societal Awareness and Acceptance

Another common issue that emerged from the focus groups was around the lack of acceptance of autism in society and how that stigma negatively affected the mental health of the participants. The themes below denote different aspects of this and what the participants need to change to better their mental health.

***Insufficient Local Awareness and Acceptance:*** There is a need for increased awareness and acceptance of autism within one's social network, including one's employer, coworkers, friends, and family. This includes receiving support and acceptance of their differences.

***Inadequate Services for People with Intersecting Identities:*** There is a need for services and supports that consider and understand the implications of the intersectional identities common in the Autistic community (e.g., gender, sexuality, ethnicity, level of ability). This includes having services that are culturally-appropriate and inclusive of BIPOC, 2SLGBTQ+ Autistics as well as having services for non-speaking Autistics. In addition, this includes a focus on the experience of Autistic women and how it differs from stereotypical autism presentations. Another current need that was discussed was services for people with different levels of ability; many services are intended for either people with lower levels of support needs or higher levels of support needs and there is not much in between.

> **For me, identity is a complicated thing with lots of overlaps. Like a person is a Venn diagram, right ? So understanding the ways that it's not like 'Okay, you're here because you are an Autistic person and that is the only thing we care about.' Obviously, everyone in this this group has talked about the way that their gender has affected their care, their self-image , their ability to connect with community. And I think that that's something to think about. But it's not just about gender. It's about all of these other ways that people are separated from one another and thinking about how that should be thought about in care. My therapy for autism isn't just therapy for autism. It's therapy that incorporates my entire identity as a person. Autism's a facet of it."**
>
> — Men's group participant, 41 years old

> **You're too big to go to the left, you're too small to go to the right, and there's a cliff right in front of you, and you are wondering what you're going to do. I'm so fed out of this, every every time it's an extra effort and strain to lift yourself and get airborne because you can't go forward."**
>
> — Men's group participant, 47 years old

***Insufficient Societal Awareness and Acceptance:*** There is a need for increased awareness and acceptance beyond one's immediate connections, at a broader, societal, level. This includes educational resources and awareness campaigns to help decrease stigma, bust myths, and address discrimination in society at large, as well as systematic discrimination through government and institutional policies.

## 3.2 Mental Health Services and Supports Barriers

Participants discussed difficulties in accessing mental health services and supports. These access barriers are thematically grouped and described below.

### 3.2.1 Barriers to Accessing Services

***Administrative Burden:*** The process of finding an appropriate mental health service, booking it, and completing any additional paperwork poses a barrier to access. Participants discussed issues such as online-only bookings with no phone alternatives, forms that are difficult to understand, lack of times available outside of work/school hours for booking appointments, and a lack of transparency in information about services and insurance coverage leading to wasted time and efforts.

# 3 | What we found: Needs and Barriers Cont'd

***Limited Delivery Modalities:*** The lack of alternatives to in-person care is a barrier to access for some. Conversely, only offering online options for some services also poses concerns for people who prefer in-person services. As was also discussed in the focus groups, in some places only short-term or crisis services are available when what is really needed are long-term services for continued outpatient mental health care.

***Affordability of Services:*** A significant barrier to accessing existing services is the high costs of autism assessments and mental health services. This is due to the fact that most of the existing services for adults are provided privately and not covered by provincial/territorial health insurance programs.

> **"Therapy and counseling is prohibitively expensive. My work covers $500 a year, which is like two sessions, and if you need help daily that doesn't help. So much more needs to be done in terms of helping people. We put a whole lot of words in the screen, but people's lives are at stake. That's the important thing. There's a whole lot of people behind all of this, and emotions, and whether they're going to survive in this in this world or not."**
>
> —Gender diverse group participant, 45 years old

***Insufficient Offerings in Rural and Remote Areas:*** There is a lack of services and supports available to those in rural and remote areas, which poses a geographical and logistical barrier to access. Also, as some participants described, services in rural and remote locations also tend to only be offered in a single modality (such as online), which can also be a barrier to access.

***Long Wait Times:*** The wait times, especially for publicly-funded services, is a very significant barrier. The waits for services can stretch to years or longer.

> **"I was on a waitlist for four years. I finally got seen earlier this year. I was put on the list either in 2019 or 2020. So it's a very long waits. Otherwise it's $5,000 or more for autism assessments for adults and like there's not that many even paid ones."**
>
> —Gender diverse group participant, 35 years old

# 3 | What we found: Needs and Barriers Cont'd

***Difficulty Navigating Bureaucracy to Find and Access Services:*** Finding relevant services and effectively navigating the system to access them is difficult. This process poses a barrier to service access. Further, the inconsistencies in services and policies between provinces aggravates the issue. Participants described being unable to know where to start in looking for services, and when they did start looking, the process was not transparent. Some mentioned having asked their family doctor for help, unsuccessfully, but not knowing where else to turn for support in finding the help they need.

> **"The way I see things, I get many people here from many provinces. I wonder if we can have organization to standardize it, to make sure nobody is left behind."**
>
> —Men's group participant, 47 years old

### 3.2.2 Barriers due to Service Design

***Limited Communication Supports and Alternatives:*** The communication challenges or differences that Autistic people may have can create barriers when services do not or cannot accommodate them. One way to accommodate this would be to provide information in different ways, such as providing both verbal information and written information for medical results. Also, there can be a need for interpreters or augmentative or alternative communication methods for some Autistic people to participate; however, this is not always supported in existing services.

### 3.2.3 Barriers to Access from the Healthcare System

The following themes relate to the role the healthcare system plays in service access that creates barriers to accessing mental health care.

***Cynicism by Practitioners about Autism Diagnosis:*** Participants reported that they had encountered practitioners who were cynical about them being Autistic, or otherwise refused to believe their autism diagnosis and value their lived experience. This manifests in different ways: from the participants being doubted because they did not fit a 'textbook' presentation of autism and then not being able to get a referral for assessment, and practitioners who feel that participants who paid to have a private assessment paid for a diagnosis and that the diagnosis is not truly valid.

# 3 | What we found: Needs and Barriers Cont'd

> **[T]he way women and girls are socialized, so if you're born and socialized female then, culturally, you're not allowed to be content. I have highly developed masking skills and it makes me not be believed because they see me being confident and competent and on top of things. And so I'm not believed when I ask for help. I'm not believed when I tell them there are problems. I've even at this point demonstrating in a neurotypical way that I have a problem and it wasn't effective."**
>
> —Women's group participant, 51 years old

> **I know I'm Autistic. I've got to be, I finally figured it out. I felt I had to have a formal diagnosis because I didn't think anybody would believe me. I figured that was the only way I could prove to to family, to work, to anybody because I had been so high masking and flown under the radar for my entire life."**
>
> —Women's group participant, 49 years old

***Service Access Control/Gatekeeping:*** The need for referrals from medical professionals, or a formal diagnosis to access publicly funded mental health supports was noted as a barrier. This included difficulty with getting a referral, restrictions of services from people who are 'not Autistic enough', as well as issues of gatekeeping via government policy and interprovincial barriers. One participant noted that they had been diagnosed with ADHD in one province but had to undergo two further assessments for re-diagnosis after moving to a different province to be able to access medication in the new province.

> **With regards to moving provinces, [...] when I needed the doctor in [my new province] to fill out a disability form, he needed my psychological assessment and he wanted the official copy from directly from the hospital. And the hospital in [my original province] had lost the psychological assessment and they didn't even communicate that to [...] the doctor in [my new province]. I ended up driving to [my old province] to go in person, find out what's going on. And that's when I found out that they lost my assessment and the doctor that did that assessment had died back in 2019. I had an assessment done in the beginning of 2017. So I do have a copy of it, just this one doctor in [my new province] didn't want to acknowledge that I had autism until he got official copy directly from the hospital that did that assessment."**
>
> —Men's group participant, 35 years old

> **There's got to be something for everybody, and whatever we do with neurodiversity has got to include everything. Diagnosis should be free for anyone with no gatekeeping whatsoever. I asked my doctor about it, she doesn't think I'm Autistic, whatever, but that doesn't help me at all."**
>
> —Gender diverse group participant, 45 years old

***Misdiagnosis:*** Many participants reported that they had received a misdiagnosis (e.g., were diagnosed with depression and put on SSRIs without exploring an autism assessment) or had their Autistic traits misinterpreted by practitioners. This misjudgement was noted as a barrier to service access; that is, not being able to access the supports they truly needed, because they did not have the diagnosis that would give them access to those supports.

### 3.2.4 Barriers to Societal Awareness and Acceptance

***Insufficient Accessibility and Inclusion:*** Participants often noted systemic level barriers to accessing services, including insufficient government policies to support inclusion, and physical accessibility considerations when accessing services, including transportation.

***Mistrust of Practitioners:*** There is a lack of trust in practitioners and the medical system that poses a barrier to accessing services due to past negative experiences. Participants reported being subject to ableist behaviour from past practitioners and some also mentioned that they did not disclose their autism diagnosis fearing discrimination, dismissiveness and loss of autonomy or credibility in working with their provider.

> **Well it's a multi layer issue. I would typically not disclose that I was Autistic because I would be afraid of being gaslit or not believed. I don't tell people typically anymore because of the bad experiences of telling people because they don't believe me . So it's like if I were to tell someone, then they wouldn't believe me. And then it's like, if I did, then there would be this weird thing."**
>
> —Gender diverse group participant, 39 years old

# Priority Area: Social Support

Participants discussed the types of community-based social supports that they needed. These have been thematically grouped and listed below.

## 3.3 Social Services and Support Needs

### 3.3.1 Community-Based Social Support

Participants discussed different types of community-based social supports and programming they needed for their mental health. These have been thematically grouped and listed below.

***Lack of Adult-Focused Supports:*** There is a need for community social support services that are focused on and exclusive for Autistic adults as many existing supports focus on children and families. In particular there is a need for supports for people over 30 years of age; the few existing supports for adults, tend to only cover early adulthood, with support ending for people in their 20s.

***Lack of supports for building Autistic Community:*** There is a need for services and supports that help convene the Autistic community socially, facilitating people to form friendships and meaningful connections with other Autistic people.

> **"I'm not saying that we should go round up Autistics and throw them in a room and you guys make friends. But something to that effect, whether that's somehow increasing community or something like that. I've heard it say that loneliness kills and that certainly is a thing. So somehow, some way of increasing community among among Autistics [would be important]."**
>
> —Men's group participant, 44 years old

***Inadequate Supports for Creating and Maintaining Social Connections:*** There is a need for services that promote social connections such as: improving social skills, understanding social cues, making friends, social meet ups with other people (not necessarily only Autistic people), and help with dating and relationships skills.

***Lack of Third Places:*** There is a need for increased availability of third spaces (places in one's life outside of work and home) where the community can gather for free and be comfortable not necessarily for social reasons.

***Insufficient Group Services:*** As with mental health services, there is a need for services and supports that are delivered to groups or in a group setting. This includes support groups, social group programming, and peer groups.

***Insufficient Supports for Daily Living Activities:*** There is a need for more support with instrumental activities of daily living such as making food, washing dishes, caring for children and more. The main type of support participants discussed that could help them was body doubling, where multiple people work together at the same time to help keep each other focused, of which two examples were frequently mentioned: support swapping networks (pairing or grouping people with complementary skills together to help each other with tasks) and errand groups (groups where people get together to do one task that everyone needs to do, but can find difficult by themselves, such as grocery shopping). Also mentioned was housing support in the form of help with chores, and also help with finding homes and moving.

> **Parallel play! I don't care if somebody is sitting in the room making art like I'm making art. I just want people to hang out with. You know, I sit here in my apartment alone most of the time. My happiest is when there's somebody here. Doesn't matter what they're doing , they could be doing something totally different than me. That's hugely important."**
>
> —Men's group participant, 47 years old

> **Having like a buddy system for more parallel play kind of thing! But for life and not just like activities. I think that having that kind of support would be incredibly helpful because going to get groceries is a lot easier when I have someone with me, [even] just as moral support. Or like, some kind of scheduling system that is like, okay, we both need to go get groceries, so let's go get groceries on Tuesday with my assigned buddy."**
>
> —Gender diverse group participant, 33 years old

***Insufficient Employment Supports:*** There is a need for activities focused on helping Autistic people get and keep their jobs. This could include accommodations at work, help managing their finances from employment, training for employers. Also discussed was the need for help getting a job, beyond help developing a resume, such as interview training, as well as helping Autistic people find jobs and helping them present the 'right' image to employers, and information on when and to whom one should disclose about being Autistic in a work environment.

***Insufficient support for Autistic parents:*** There is a need for more social services and supports focused on parents. This includes social groups for parents as well as peer support groups that have parenting as a main theme. In addition, assistance with childcare and support for extended family members was mentioned.

***Insufficient Offerings:*** There is a general need for more community-based social supports for Autistic people, especially adults. This is particularly true in rural and remote communities.

***Lack of Variety in Support Programs:*** Overall, there is a need for a variety of different kinds of programming to help the Autistic community with different interests (e.g., groups revolving around special interests such as photography, hyperfixation swap groups, board game days).

> **Hyperfixation craft swap group? Like 'I went crazy buying supplies for this craft years ago and haven't touched it in years, but I can't afford to do that with the next crazy craft trend I wanna do— wanna swap?'"**
>
> —Women's group participant, 35 years old

### 3.3.2 Service Logistics and Design

The needs below are related to the design and delivery of social support programming to best support the participants' mental health.

***Lack of Autistic-Led and Autism-Focused Services:*** There is a need for services that are led or designed by Autistic people, people who deeply understand the lived experience of being Autistic. There is also a general need for programming specifically for Autistic or neurodivergent people.

> **I've heard people say 'nothing about us without us'. And I really agree with that. I think that, wherever possible, services for Autistic or neurodivergent people should at least partially be run by people who experience the world the way that we do so that they can... I mean, not that it's a cookie cutter solution, but at least some of the perspective is coming from a similar place."**
>
> —Gender diverse group participant, 33 years old

***Inadequate Supports for People with Intersecting Identities:*** There is a need for services that consider all intersecting identities of participants (e.g., female Autistics, people with differing levels of support needs). Programming for Autistic people with specific intersectional identities that were mentioned in the focus group included groups for 2SLGBTQIA+ Autistics, Autistic women, BIPOC Autistics, and groups for people with different levels of support needs.

> **I do find autism and neurodiversity alone to be kind of too broad of a category to appeal to me or guarantee that I will get along with people in it. So the intersectional identities thing is very much like it's like, okay, Autistic and something else like gives me a lot more to go on, I think. And also groups around shared activities or special interests that sometimes happen to just attract a lot of neurodivergent people have worked very well for me too."**
>
> —Gender diverse group participant, 39 years old

***Insufficient Information about Programming:*** There is a need for programs to provide explicit instructions and expectations for their services. People need to know what they are getting into, what the expectations are, where events are and more, so that they can plan and make informed decisions. Without transparent information being available ahead of time, participants reported being less likely to participate.

> **If [me and my Autistic friends are] going to go out to like a restaurant, we check the menu ahead of time. We look at the seating, whether, you know, it's going to be a comfortable environment and we might check where the parking is. We want to know everything about this. And like if these groups just have vague amounts of information, I don't even know if that's going to be helpful for me or if I'm just going to be too anxious to enjoy myself."**
>
> —Gender diverse group participant, 45 years old

***Insufficient Sensory Supports:*** There is a need for services and programs that consider sensory needs and accommodate them. There is also a need for social spaces to be generally aware of sensory concerns. Services that were mentioned in the focus groups included quiet hours in stores, sensory hours in other public spaces such as libraries, museums and gyms, and movie nights including captions or subtitles.

### 3.3.3 Societal Inclusion

***Insufficient Supports for Advocacy:*** There is a need for programs that focus on advocacy as a common theme for convening and/or programs that support Autistics advocating for themselves, including in workplaces and to government and social services agencies.

***Insufficient Supports to Build Awareness and Acceptance:*** There is a need for services that help improve autism awareness and acceptance in society and that are truly inclusive. This includes having services that are inclusive of neurodiversity more generally, as well as providing educational resources and outreach to the general public about autism to raise awareness in this area. In support programming, it is also important to address lateral ableism to make spaces safe for all.

> “**I think that training/education for Autistic people by Autistic people with up-to-date correct information that's not just like: 'Here's how you train Autistic children to behave like they're all allistic!'. Because a lot of the diagnosis and it's like: 'Okay, congrats, go out into the world, figure it out.'”**
>
> —Gender diverse group participant, 36 years old

## 3.4 Social Support Barriers

### 3.4.1 Barriers to Accessing Community-Based Social Support

***Limited Delivery Modalities:*** Many programs only offer in-person or online services but not both, and the type of programming can be a barrier to access. Some participants also discussed specific concerns about safety in online programming, rigidity in attendance policies, and activities focussing only on verbal communication as barriers to accessing and engaging with support programs.

***Logistics and Scheduling:*** The logistical aspects of participating in activities such as scheduling can pose a barrier to access. This includes issues with transportation to and from activities, events not being child-friendly, forcing parents to find babysitting to be able to participate, and many programs only being offered during typical working hours; when working, people would not be able to participate.

> “**The other piece of the puzzle is for some people transportation to and from events is an issue because a lot of folks, again, it's money... Maybe they don't have a car, they don't have a license. So they need a way to get there and back.”**
>
> —Men's group participant, 60 years old

***Service Access Control/Gatekeeping:*** The need for referrals or a formal diagnosis to access publicly funded community-based social supports was noted as a barrier. Some participants noted that they had had issues accessing certain services because their diagnosis came from a specific type of professional that was not recognized by the support program they were trying to access.

***Difficulty Navigating Bureaucracy to Find and Access Services:*** Having to navigate the system to find and access services is a barrier to accessing them. Many community-based social support services are not centrally listed in a single place and some participants noted that they had no idea what sorts of community-based services were in their community or if they would even be eligible for them.

### 3.4.2 Logistics and Design Barriers

The access barriers below are ones that are caused by how social support programming is designed and delivered.

***Energy Demanding Programming:*** Participants reported struggling with Autistic burnout and exhaustion, and that being a barrier to both finding and engaging in community-based social supports. Participants discussed how many existing social support programs take a lot of time and energy to find, apply for, attend and participate in.

***Insufficient Information about Programming:*** A lack of explicit instructions about programming is a barrier to access. In addition to a description of the services, potential participants want to know what they are signing up for, what they can expect, and many will need the information to prepare themselves. This information must be available in accessible formats.

***Pressure to Mask in Programming:*** Participants reported needing to mask (hide their Autistic selves and consciously adjust their persona) to fit in and to be able to attend programming and noted this as a barrier to accessing them. Some participants who experienced this also noted that the lack of being able to be oneself in group programming and the pressure they felt to conform left them feeling resentful and needing more recuperation time after participating.

> **"Community is a thing that I've been thinking about a lot lately, and I think that it's something that people in general have a really hard time connecting with. I think even neurotypical people really struggle. It's just that with neurotypical people, especially straight, monogamous, like White, cisgender neurotypical people, they have a script that they can kind of follow and that can create the sense of community, even if that's not necessarily what they're experiencing. And I think that for Autistic people who do not necessarily have access to or who don't want to mask to perform that script, you're really starting from the ground up."**
>
> —Men's group participant, 41 years old

***Unstructured Social Programming:*** Participants reported a lack of moderators or facilitators within services who can manage the social dynamics of group activities as a barrier to participating. Without a moderator, some participants reported that they had experienced bullying and arguments in social support activities in the past and did not feel safe. Everyone needs to be able to participate as well as contribute and without someone moderating the discussion, a couple of people can dominate the discussion.

***Lack of Belonging and Safety:*** Participants reported not feeling like they belonged in a space as a barrier to entering it and accessing services. This was due to past experiences, restrictive criteria around who can or cannot participate, as well as not being able to be themselves in the program.

***Social Interaction:*** Social interactions, communication challenges, and the associated stresses are barriers to accessing services. Some participants noted that past support and social groups they participated in were heavily focused on verbal social interactions and said that they felt forced to engage. They also discussed how they feared their words or social cues being misunderstood and leading to awkward and uncomfortable interactions.

> **"I didn't even recognize that I had high support needs until I started deep diving into what Autistic traits are and how they show up. I didn't realize that my day to day exhaustion is because of the brain Olympics I have to do just to exist in a conversation."**
>
> —Gender diverse group participant, 38 years old

### 3.4.3 Barriers to Societal Inclusion

***Affordability of Supports:*** Money was highlighted as a significant barrier to accessing community-based social services due to their high cost. Money for travelling to and from in-person programs was mentioned, with it being a particular issue in rural and remote areas. Also, some hobby groups and help services for daily living (e.g. cleaners) are too expensive to access.

***Insufficient Accessibility and Inclusion:*** Participants noted systemic level barriers to accessing services, including insufficient government policies to support inclusion, and physical accessibility considerations when accessing services. This includes issues where subjective assessments are needed to access services. Some participants reported being told that they were 'too normal' to need support, or being presented services with condescension, which led to people being hesitant to ask for help or access supports in the first place.

# 3 | What we found: Needs and Barriers Cont’d

> **A major challenge to my mental health as an Autistic person is that I’ve been high masking my whole life. So because I can talk, and I have a friends and a bachelors degree, I’m not disabled enough to be allowed to have accommodations. This is the ongoing struggle in narrative.”**
>
> —Gender diverse group participant, 38 years old

> **I would never say autism is a barrier. […] I would say society’s lack of knowledge and skills around autism is the barrier. I think when we say autism is the barrier, we’re making it a medical model statement. So if autism is the barrier, the cure or the solution is to fix autism. Whereas if we say society is the barrier, the solution is to fix society.”**
>
> —Women’s group participant, 40 years old

# 4 | Recommendations to better support Autistic adults from Autistic adults

After identifying needs and barriers related to mental health and social support services, participants were asked to make recommendations to inform solutions from their unique perspectives. The recommendations were categorized into three areas: mental health services, community-based social support, or both. Each participant then prioritized their top three recommendations. This section outlines these consolidated recommendations, organized by themes that address both service improvements and access barriers, emphasizing the need for increased accessibility and inclusivity in autism services and advocacy.

It is essential that these recommendations result in action. To this end, the Alliance team has developed potential pathways for implementation within the grey boxes: some potential next steps that government, Autistics, researchers and civil society can take in response to the recommendations in this report.

These are not the only possible steps. They are presented to ground a conversation on how to achieve the recommendations made in this report, and are meant for debate, addition, refinement, or further study.

## 4.1 Access to Services and Supports

### 1. Expand Adult-focused Autism Services

- Publicly fund and enhance adult-focused autism services, including diagnostic services.
- Extend services available to Autistic children, such as service animals, to benefit Autistic adults.
- Address the overall lack of affordable adult-focused autism services.

### 2. Enhance Support for Caregivers and Families

- Develop and provide targeted support for caregivers of Autistic adults and their chosen families, as well as specific assistance for Autistic parents.

### 3. Improve Employment Supports

- Implement and expand supports for Autistic job seekers, including opportunities for remote work and flexible scheduling, establish dedicated employment agencies, and enforce laws to protect Autistic people from workplace discrimination.

# 4 | Recommendations to better support Autistic adults from Autistic adults Cont'd

**4. Increase Financial Supports**

- Ensure better access to financial assistance, including tax benefits and general financial support such as Universal Basic Income, to help cover the increased costs of daily living.

**5. Broaden Mental Health Services**

- Publicly fund a wider range of mental health services and increase capacity within the mental health system.
- Address long waitlists and ensure consistent support by including occupational therapists, psychotherapists, and counselors in the available services.

## Potential action areas for Access to Service and Supports

*In order to make the recommendations from the Canadian Autistic Adult Needs Assessment a reality, government, Autistics, researchers, and civil society groups can work to:*

**1. Expand Adult-focused Autism Services**

*Expand adult-focused autism services*

- Building on previous work within the sector mapping existing services, develop a comprehensive gap analysis highlighting specific areas requiring enhancement and funding and the barriers to expansion

*On diagnostic services*

- Develop workforce strategy options to increase the pipeline of professionals qualified to provide a diagnosis, including engaging with PSE sector and professional colleges and associations
- Consider the role of governments, including the federal government, in building capacity among primary health care providers

# 4 | Recommendations to better support Autistic adults from Autistic adults Cont'd

- Work to identify a broader range of professionals who could perform or contribute to diagnoses
- Assess billing models under provincial and territorial public health insurance plans, and other potential barriers to providers providing publicly funded diagnostic services
- Work collaboratively with private extended healthcare benefit providers to consider their internal policies (e.g. adding more providers to their lists of approved diagnostic services providers) and encourage employers to consider the quality of these services when choosing insurance providers

*On service animals*

- Work with provincial and territorial governments to develop options to ensure Autism service dogs are available for adults with benefits like guide and service dog supplements.

*On affordability*

- Explore options to offer financial assistance to Autistics. For some this could include changes to expand access to the disability tax credit, enhance the Canada disability benefit, and improve other programs for people who identify as having a disability, for others it could be general income supplements and financial assistance. See also below at "4. Increase Financial Supports".
- Explore options to offset the expense of Autism services including changes to and expansion of the medical expense tax credit.
- Assess gaps in providers with expertise in adult services and how this contributes to expense (see also above re: workforce development)
- Explore service models that are lower barrier and cost, especially in different modalities where appropriate, and for people for whom these options work well.

# 4 | Recommendations to better support Autistic adults from Autistic adults Cont'd

**2. Enhance Support for Caregivers and Families**

- Identify supports which are most important for caregivers and families (e.g. financial supports, access to services, affordability of services, systems navigation, respect and standing in medical settings, etc.)
- Identifying which parts of those supports are highest priority for improvement, (transportation, publicly-funded DSWs, PSWs, respite, etc.)
- Articulate the roles of different orders of government in improving how these services are delivered and funded (e.g. whether changes are required to overall funding levels, design choices from local health systems, etc.)
- Explore new types of financial support and enhanced financial supports like caregiving credits, expanding medical expense tax credits, etc.

**3. Improve Employment Supports**

- Map the roles of different actors and levers in the employment ecosystem when it comes to supporting Autistics
- Develop proposals for changes to government funded skills development programming, including EI-funded programming.
- Explore best practices for tailored supports and wrap-around supports (in addition to core employment supports) to make services more accessible to Autistic job seekers
- Build capacity in the employment and skills development sectors to make sure professionals are better able to support Autistics
- Consider which provinces and territories are leading and which are lagging in the appropriateness and usefulness of their employment and skills service delivery models
- Develop proposals for changes to provincial disability support employment programs or social assistance employment support, as applicable

# 4 | Recommendations to better support Autistic adults from Autistic adults Cont'd

- Identify which sectors and types of work are the highest priority employers for Autistics, in terms of interest, potential to be welcomed, and overall fit.
- Map pathways for government and employers to make these sectors accessible (e.g. career development services, skills development services, employer-education, tax incentives)
- Work with employment networks such as chambers of commerce to identify pathways to employment, including sector-based solutions for training and capacity building for SME employers
- Scan for gaps in employment law and enforcement (e.g. employment standards enforcement vs. access to legal service for private suits against employers vs. the law itself providing inadequate protections)

**4. Increase Financial Supports**

- Determine how many Autistics receive existing forms of disability specific financial assistance (e.g. DTC; provincial disability support programs, new CDB) or saving incentives (e.g. RDSP), and non-disability targeted supports (like the Canada Workers' Benefit) and non-income supports (e.g. housing supports) and average amounts of support they receive
- Determine the gap between existing support and needs experienced by Autistics
- Map barriers to receiving financial assistance (e.g. DTC eligibility)
- Articulate the design changes required to improve access to financial assistance. Options include increasing assistance amounts in some or all benefits; making benefits easier to access; making existing tax benefits refundable; changing income thresholds for programs targeting low-income people; developing new types of benefits, including for people who do not 'qualify' or identify as having a disability (e.g UBI)

**5. Broaden Mental Health Services**

- Map the gaps in private and public mental health services, especially those tailored to or safe for Autistics, focusing on known areas of need such as pipeline of trained professionals with expertise in servicing Autistics

- Identify and evaluate existing and planned efforts to increase mental health capacity across provincial and territorial health and social systems in terms of their abilities to fill the gaps in service
- Enhance existing commitments with plans to fill service gaps, including making connections directly to Autistics and health providers through developing effective referral pathways for both publicly and privately funded supports

## 4.2 Involvement and Advocacy

### 1. Lived Experience Committees

- Establish lived experience committees to inform program development and delivery to ensureAutistic people have a role in the design and implementation of services/supports.

### 2. Service Provider Diversity

- Increase the offering of, and fund opportunities for, Autistic and neurodivergent people to enter the system as service providers.

### Potential Action Areas for Involvement and Advocacy

*In order to make the recommendations from the Canadian Autistic Adult Needs Assessment a reality, government, Autistics, researchers, and civil society groups can work to:*

**1. Lived Experience Committees**

- Articulate promising practices for service organizations to include people with lived experience in program development and delivery (e.g. what are the characteristics of an effective committee, what are the best standards for compensation, group structure, material and discussion format, and how to ensure advice is incorporated at every stage)

# 4 | Recommendations to better support Autistic adults from Autistic adults Cont'd

- Explore options for 'upstream' representation from Autistic people at the level of government and other funders who direct funds to service providers. Examples include expert advisors to Deputy Ministers; expert panels which undertake a review of a particular issue; standing advisory committees; enhanced consultation processes for changes to services for Autistics
- Explore the use of citizen's assemblies and other democratic innovations as a way of fore-grounding lived experience in decision-making
- Set measurable goals to move from policy-making by consultation to codesign with the community

**2. Service Provider Diversity**

- Identify leading examples of encouraging and supporting Autistic professionals in the service system; including mentorship and networks to support the next generation of Autistic professionals
- Explore options to incentivize employment and advancement of Autistics, including tax incentives and job grant programs for service provider employers
- Work with industry networks and professional associations to raise awareness and develop plans for active recruitment and retention of Autistics into service professions

## 4.3 Healthcare and Diagnosis

### 1. Education and Training for Providers

- Develop and deliver education and training programs for healthcare providers to help eliminate stigma, increase awareness, decrease misdiagnosis, and address intersectionality and autism.

### 2. Coordination and Continuity of Care

- Increase coordination and continuity of care across healthcare providers, including physical and mental health services, with a focus on holistic, intersectional, gender-informed, and neurodiverse-affirming care.

# 4 | Recommendations to better support Autistic adults from Autistic adults Cont'd

**3. Access to Assessment Documentation**

- Provide people who undergo an autism assessment access to their assessment paperwork to advocate for themselves in accessing care and supports.

**4. Defined Pathways to Care**

- Develop a defined pathway to care/autism services, including systems for referrals that do not rely solely on a family physician.

## Potential Action Areas for Healthcare and Diagnosis

*In order to make the recommendations from the Canadian Autistic Adult Needs Assessment a reality, government, Autistics, researchers, and civil society groups can work to:*

**1. Education and Training for Providers**

- Collaborate with professional schools and professional associations on autism training and ongoing professional development to raise professional capacity and reduce stigma

- Consider the role of government in supporting capacity building of new and existing primary care providers in autism

- Building on existing education programs. Explore models for collaboration between Autistic leaders, researchers, and professional associations to develop certification in neurodiversity-affirming care, with a focus on Autistic adults and spread and scale those that exist.

**2. Coordination and Continuity of Care**

- Explore options to leverage emerging tools like better electronic medical records and record sharing to avoid Autistics having to re-tell their stories and re-establish the details of their medical history with each medical professional

# 4 | Recommendations to better support Autistic adults from Autistic adults Cont’d

- Consider models for Autism-friendly, multi-professional, medical practices to enhance coordination between professionals, either in the form of specialty clinics, or enhanced training and capacity building for existing group practices
- Explore options to build Autism service navigation into regionalized care models (like local health networks)
- Explore models for certification in neurodiversity-affirming care and gender-informed care

**3. Access to Assessment Documentation**

- Raise awareness of their rights to access and correct medical records under provincial and territorial health privacy legislation
- Explore options to build capacity for advocates and service navigators on the issue of rights to medical records
- Work with provincial and territorial privacy commissioners, as appropriate, to raise awareness of existing complaint mechanism for inadequate access to records
- Conduct a gap analysis to map the cases in which health privacy legislation is inapplicable or ineffective in granting access to assessment documentation, and whether complaints mechanisms are themselves accessible and effective

**4. Defined Pathways to Care**

- Identify key practitioners and touchpoints, beyond family physicians, who work with Autistics in need of service referrals
- Explore options for government and service providers to develop a comprehensive, consistently updated, referral resource for practitioners and Autistics themselves

# 4 | Recommendations to better support Autistic adults from Autistic adults Cont’d

## 4.4 Public Awareness and Acceptance

### 1. Stigma Reduction

- Produce and disseminate more resources to foster public awareness and acceptance of autism, reduce stigma, and address myths and misconceptions.

- Business and Employer Resources

- Create and publicize resources for businesses and employers to support inclusivity and understanding.

## Potential Action Areas for Public Awareness and Acceptance

*In order to make the recommendations from the Canadian Autistic Adult Needs Assessment a reality, government, Autistics, researchers and civil society groups can work to:*

### 1. Stigma Reduction

- Map best practices for stigma reduction and examine campaigns and initiatives from other jurisdictions that have had measurable success

- Consider the benefits and challenges with broad campaigns vs. targeted (e.g. campaigns for certain types of employers, for service providers, for people who lead organizations)

- Explore role of key private sector industries, for example media, in showing diverse, rich, and varied representations of Autistics in popular culture (e.g. companies setting standards for on-screen and behind the scenes representation)

### 2. Business and Employer Resources

- Work with employer and business groups to try and achieve change and awareness at scale, for example by engaging boards of trade, chambers of commerce, industry associations.

- Partner with peer organizations working in the broader space of improving business and employer support for general DEI, to ensure neurodiversity is always a part of the conversation

## 4.5 Community-Based Social Supports

**1. Support Groups and Social Activities**

- Develop and offer online and in-person support groups, peer or mentorship groups, gender-specific support groups, social support groups for those over 30 years of age, and social activities with flexibility.

**2. Specialized Social Supports**

- Provide supports for meeting other Autistic people, improving social skills, dating and sexuality, themed social groups (e.g., business owners), and body doubling or parallel play opportunities.

**3. Daily Living and Physical Activity**

- Increase the offering of support with daily living activities (e.g., grocery shopping, cooking) and physical activity (e.g., fitness classes).

### Potential Action Areas for Community-Based Social Supports

*In order to make the recommendations from the Canadian Autistic Adult Needs Assessment a reality, government, Autistics, researchers, and civil society groups can work to:*

**1. Support Groups and Social Activities**

- Map the funding and program landscape for publicly and privately funded and organized support groups

- Assess the levels of evidence and measurement affirming the importance of these groups to Autistics, with a goal of having an evidence base to seek enhanced funding and new programs from government, not-for-profit and private funders

**2. Specialized Social Supports**

- Explore models for government, civil society, not-for-profit and private sector to support community-led and social initiatives on a sustainable basis
- Identify key actors like Business Improvement Areas who can show leadership in creating and upholding Autistic-friendly public and semi-public spaces

**3. Daily Living and Physical Activity**

- From a health perspective: Assess the levels of support available at local health networks (which are the leading publicly available providers of at-home assistance with activities of daily living), and the extent to which they support, or could be expanded to support, independence, social determinants of health and preventative medicine
- From a community participation perspective: map existing services and supports and look for opportunities to scale them up, enhance them, and tailor them to different communities
- Draw best practices and partner with community organizations that support people with other identities with daily living (e.g. senior support groups) to tap into both professional expertise and existing volunteer networks - while adapting the practices and building capacity with partners to meet the specific needs of Autistics

## 4.6 Research and Evidence-Based Practices

### 1. High-Quality Research

- Fund and carry out more high-quality, evidence-based research into autism, including the role of hormones, autism across the lifespan, and autism in women and other intersectional groups.

# 4 | Recommendations to better support Autistic adults from Autistic adults Cont’d

## Potential Action Areas for Research and Evidence-Based Practices

*In order to make the recommendations from the Canadian Autistic Adult Needs Assessment a reality, government, Autistics, researchers, and civil society groups can work to:*

**1. High-Quality Research**

- Partner with tri-council federal granting organizations, universities, and philanthropic groups to identify funding opportunities targeting research on issues facing adult Autistics, including looking at models of collaborative high-quality research (like living literature reviews/systemic review, open evaluations) that improve the quality of and access to research and evidence
- Ensure as much research as possible relating to adult Autistics is available on a free, open-access basis, including to people not affiliated with universities.

## 4.7 Barriers to Access

**1. Information and Navigation**

- Provide clear, accessible information beforehand for all services and supports.
- Increase support for navigating and accessing services, including clear information about availability, eligibility, and assistance in navigating the system.

**2. Simplified Forms**

- Use simplified, clear, plain language in services/supports’ forms to avoid creating additional barriers.

**3. Public Funding and Accessibility**

- Publicly fund adult autism services, including diagnostic services to help alleviate the significant financial barriers that exist for obtaining services, and to help increase capacity in the mental health system to address long waitlists and access issues.

# 4 | Recommendations to better support Autistic adults from Autistic adults Cont'd

**4. Referral Systems**

- Develop and implement a system for referrals that does not solely depend on a family physician, and make at least a portion of supports or services accessible without a formal diagnosis.

## Potential Action Areas for Barriers to Access

*In order to make the recommendations from the Canadian Autistic Adult Needs Assessment a reality, government, Autistics, researchers, and civil society groups can work to:*

**1. Information and Navigation**

- Explore options to build best practices for accessible information and pre-sending information into both professional education and certification programs for service providers and professionals
- Work with governments to build neurodiversity into accessibility standards for all government services (e.g. drivers license renewal, tax filing, employment services) starting with highest-impact areas for Autistics)
- Make accessibility for neurodiverse people a named priority for existing service-delivery improvement efforts
- Explore options to build publicly funded system navigation services including improved referral systems, see above at section 4.3
- This could also be combined with multi-professional practices, see above at 4.3 (e.g. diagnostic practitioners referring people to their colleagues who assist with systems navigation)

**2. Simplified Forms**

- Articulate best practices for plain language specifically for Autistics

# 4 | Recommendations to better support Autistic adults from Autistic adults Cont’d

- Set timelines and goals for when all government services will be delivered in plain language, prioritizing those services specifically for Autistics
- Set targets to reduce administrative burden in service design, including incorporating best practices such as pre-filling forms where possible, using the ‘ask once’ principle of service design
- Seek active feedback from Autistic communities on the design of forms and other government touch-points, and commit to continuous improvement of these processes

# 5 | Conclusion

Phase 1 of this project highlighted that Autistic adults in Canada don't have the access they need to mental health services or social support: in the Canadian Autistic Adult Needs Assessment Survey, 74.7% of respondents indicated that they did not have sufficient access to mental health services to completely meet their needs and 87.5% of respondents indicated that they felt left out or isolated from others at least some of the time.[11]

In this second phase of the Canadian Autistic Adult Needs Assessment project, we explored these areas focusing on services. As can be seen in this report, Autistic adults are struggling. They have significant needs in terms of mental health services and community-based social support services, and they face significant barriers in accessing the few existing services. However, solutions do exist, and it is time to address these challenges.

The recommendations made by Autistic adults in focus groups, along with those proposed by the Autism Alliance team, offer clear actions for Autistic people, service providers, governments, and civil society organizations to implement. These actions are grounded in the lived experiences of Autistic adults and reflect their specific needs. We acknowledge there may be ongoing work aligned with the proposed actions and urge leaders and organizations to collaborate and work together to fill critical gaps in services for Autistic adults in Canada.

While progress is being made, much remains to be done. This study underscores the importance of hearing directly from Autistic adults about their needs and how to better support them. Autistic people are best equipped to tell us what they need and the challenges they face. WIth the insights from this report, services can be improved, barriers reduced and support enhanced. We call on organizations, policymakers, and advocacy groups to take up this important work and to commit to meaningful changes. Let's act with urgency to bridge these gaps and deliver on the promise of equitable support for all.

It is time to push for these changes now.

### Call to Action

First, we need resources and attention directed towards the development of services and supports for Autistic adults.

Second, change is possible when we work together.

To truly support Autistic adults, they must be involved in designing and evaluating the services meant for them. Collaboration between Autistic people, system leaders, decision makers, community organizations and advocates is essential to create effective solutions that address real needs and make lasting impact.

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