



Autism
Alliance of Canada

Alliance canadienne de
l'autisme

Fostering Inclusion: Exploring the Needs of Autistic Adults in Canada

An Autistic-led Survey

Report

April 2024

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Special Thanks

We would like to express our sincere and heartfelt appreciation to the exceptional people who have been integral in the journey of this project. To the Autistic people whose participation, insights, and leadership have shaped the very fabric of our initiative, we extend our deepest thanks. Your invaluable contributions have been the driving force behind our mission, bringing authenticity and depth to our work.

We also want to acknowledge the dedicated members of Autism Alliance of Canada, whose unwavering commitment has been instrumental throughout the development of this project. The collaborative spirit and expertise they brought to the table have been indispensable, and we are grateful for the strength of our partnership.

Furthermore, our sincere gratitude extends to our partners and generous funders, especially the Public Health Agency of Canada and the McMaster University Autism Research Team. Your support has not only provided the resources needed for this endeavor but also demonstrated a shared commitment to making a positive impact on the lives of Autistic Canadians and their loved ones. This report stands as a testament to the collective efforts of all those involved.

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, policy makers, and autism organizations across Canada. United as a shared leadership movement, we are committed to advancing autism research and policy, ensuring 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 regions. Working closely with government, we integrate lived experiences with national expertise to effectively shape autism policies. Emphasizing meaningful inclusion, we actively involve Autistic people in our projects, leading initiatives, providing policy briefings to senior-level officials, participating in research and priority-setting, and supporting Autistic scientists and trainees to lead impactful initiatives in both research and policy realms.

How to cite this document

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This report was developed by Autism Alliance of Canada in partnership with McMaster University. Autism Alliance of Canada's Board approved this project.

A Word from our Research Lead

Dear Members,

I am pleased to present to you the findings of our recent research project focused on understanding the real-life needs of Autistic adults in Canada. This project means a great deal to me and took me back to my 'research roots' in a very important way. When I was in graduate school and I started doing research, I realized that my interactions with other Autistic people did not match what the research literature said. So I planned a project around starting to fill that gap in the research and correct the misconceptions. My hope is that this project does the same and fills a gap in our knowledge.

When I was reviewing the literature in preparation for this project, there were other projects that used questionnaires but the questions could be confusing, ambiguous, or vague. For this survey, I wanted to make sure that the questions were more clear and understandable, not just to me but to other Autistics in general.

I also wanted this project to identify and address the real life needs of Autistic adults in Canada. We recruited ten lived experience partners, nine of which were Autistic, who were integral to this project. I thank them from the bottom of my heart for their help. From the initial draft of the survey, they added whole sections and reworded, changed, added, or removed questions to ensure that the survey was covering topics that were important to Autistics and that the questions were more straight-forward and more accessibly worded. We went through multiple iterations of the survey until we had one that everyone agreed was ready. Several of the partners also helped with going through the online survey platform to provide guidance on improving the user experience, with Autistics in mind. Without their help, this project would not have been as successful as it was, and I will always be grateful.

—Dr. Mackenzie Salt

A Word from our Scientific Director

We are grateful for the funding from the Public Health Agency of Canada to carry out this important work. This initiative marks a significant milestone in our efforts to understand and address the needs of Autistic adults in Canada.

The importance of this project cannot be overstated. It represents the first survey tailored specifically for Autistic adults, with the design and leadership being spearheaded by an Autistic researcher alongside members of the Autistic community. This collaborative approach underscores the success of community-driven research, showcasing our collective ability to generate evidence that authentically captures the multifaceted experiences within the Autistic community.

The findings from this work shed light on the profound needs and glaring inequities faced by Autistic adults, highlighting the critical need to prioritize equitable access to supports and services for Autistic people nationwide, irrespective of their geographical location. While many of the findings may not come as a surprise to Autistic adults and their loved ones who experience these challenges firsthand, the presentation of empirical data renders the obvious undeniable.

Such data is vital not only to validate lived experiences but also to inform policy makers, researchers, and practitioners who may not be intimately familiar with these issues. By providing concrete evidence, this information becomes invaluable in shaping decisions and initiatives aimed at improving the lives of Autistic people and their families. These findings will play a role in informing the development of Canada's first-ever National Autism Strategy, ensuring that the voices and experiences of Autistic people are central to shaping policies aimed at enhancing their well-being and inclusion.

It is essential to acknowledge that while this survey represents a significant step forward, it does not capture the entirety of the Autistic population. There remains much work to be done in ensuring that individuals with higher support needs, those residing in rural and remote locations, and other marginalized groups are adequately represented and their needs are addressed.

I wish to extend my deepest appreciation to the dedicated team at Autism Alliance of Canada for their unwavering commitment and tireless efforts in bringing this project to fruition. Their dedication and passion have been instrumental in driving this initiative forward.

In closing, this project has been driven by the urgent needs of our members. We trust that the findings will serve as a valuable resource for Autistic people and their advocates, empowering them to inform their own work and advocate for necessary changes within systems. Thank you once again for your invaluable support in advancing our shared mission of creating a more inclusive and supportive society.

—Dr. Deepa Singal

Language and Terminology

Language Statement

The way 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.

What To Know Before Reading This Report

Points of View

This report presents the data and results from the Adult Needs Survey. The interpretations and suggestions included are from the authors, relying on the survey results and their knowledge and experience.

Quotes

This report contains quotes from the survey participants. We didn't change any content in their responses, keeping them as they were submitted. The quotes are set apart from the main text with quotation marks. We decided not to edit the original comments, including any spelling or grammar mistakes, to keep the participant's voice authentic. We added details like age and gender for context, but removed personal information to protect privacy — information presented in brackets has been changed to that end.

Result Presentation

In this report, we've simplified the results by rounding them to the nearest percent for easier understanding. A more detailed report, along with the complete dataset, will be made public when available.

What You Can Do With This Report

As a Policymaker

This report is a valuable tool, offering you insights into the essential needs and priorities of Autistic adults in Canada. It highlights what matters most to the Autistic community regarding their health and wellbeing. You can use this information to shape initiatives, including informing the implementation of Canada's National Autism Strategy and policies at the provincial and territorial level. The report provides a roadmap for focusing on key areas, and can ensure future policies are inclusive and directly address the specific concerns of Autistic adults. Its goal is to guide policymakers toward a more effective and targeted approach for improving the lives of Autistic adults in Canada.

As a Researcher

This report is a useful tool for thinking about what we still need to understand about the needs of Autistic adults in Canada. It talks about their current situations and what needs to be different, which might spark your interest in exploring new research topics. By exploring Autistic adults' current situations and highlighting areas that require change, it not only informs but also inspires further exploration into new research topics. Researchers can use this report to pinpoint gaps in understanding the nuances of Autistic adults' needs and develop new approaches, in collaboration with the community, to address the challenges they face. This document, filled with perspectives and observations, provides a solid foundation for future research efforts aimed at improving the well-being of Autistic adults in Canada.

As a Community Leader

Leverage this report as a powerful tool to engage your community members in meaningful conversations. Use it as a catalyst for gathering diverse opinions on the current state of affairs for Autistic adults in your area. By understanding their perspectives, you can effectively advocate for the specific needs highlighted in the report. Use the data in this report as a strong base to make decisions based on facts, making sure we use our resources where they'll have the most impact.

As an Advocate

This report is a good starting point for when you talk to policymakers and other advocates about the needs of Autistic adults in and beyond your local area. You can bring these insights to the attention of your local government, fostering awareness and advocating for policies that address the unique challenges faced by Autistic adults. This report empowers you to be a bridge between your community and local authorities, ensuring that their voices are heard and their needs are prioritized in shaping policies that make a tangible difference in the lives of Autistic adults.

The Report

Introduction

What is life like for Autistic adults? Apart from stories shared by families and individuals through art, storytelling, and social media posts, we have limited information about the needs and life experiences of Autistic people in Canada once they reach their early 30s and beyond.

Most autism research focuses on children, leaving big gaps in understanding Autistic adults. We need to know more about their lives, how they experience quality of life, independence, daily activities, and feelings of loneliness, mood, and mental health. By better understanding the needs and lived experience of Autistic adults, we can focus research and policy actions on the areas that are most important to this population, in turn improving the lives of Autistic Canadians and their loved ones.

I'm pretty sad to learn how little is available to me as an autistic adult.

— 37 year old genderfluid
Autistic person

I have received no resources and can not find any resources for autistic adults in [my province]. It has been very disappointing to see the lack of resources for adults with almost all of them being for young children.

— 31 year old Autistic man

What we did: A national survey

In partnership with the McMaster University Autism Research Team, we carried out a nationwide survey to learn more about the needs of Autistic adults aged 30 and older in Canada. This survey was led by an Autistic researcher, Dr. Mackenzie Salt, and guided by an advisory team of Autistic adults, making this a project “for Autistic adults, by Autistic adults”.

Study Goal

The data collected will be used to shape autism policies in Canada. It will also help plan future research to better support the health and wellbeing of Autistic adults in the country. We set out to answer three main questions:



Developing and Sharing the Survey

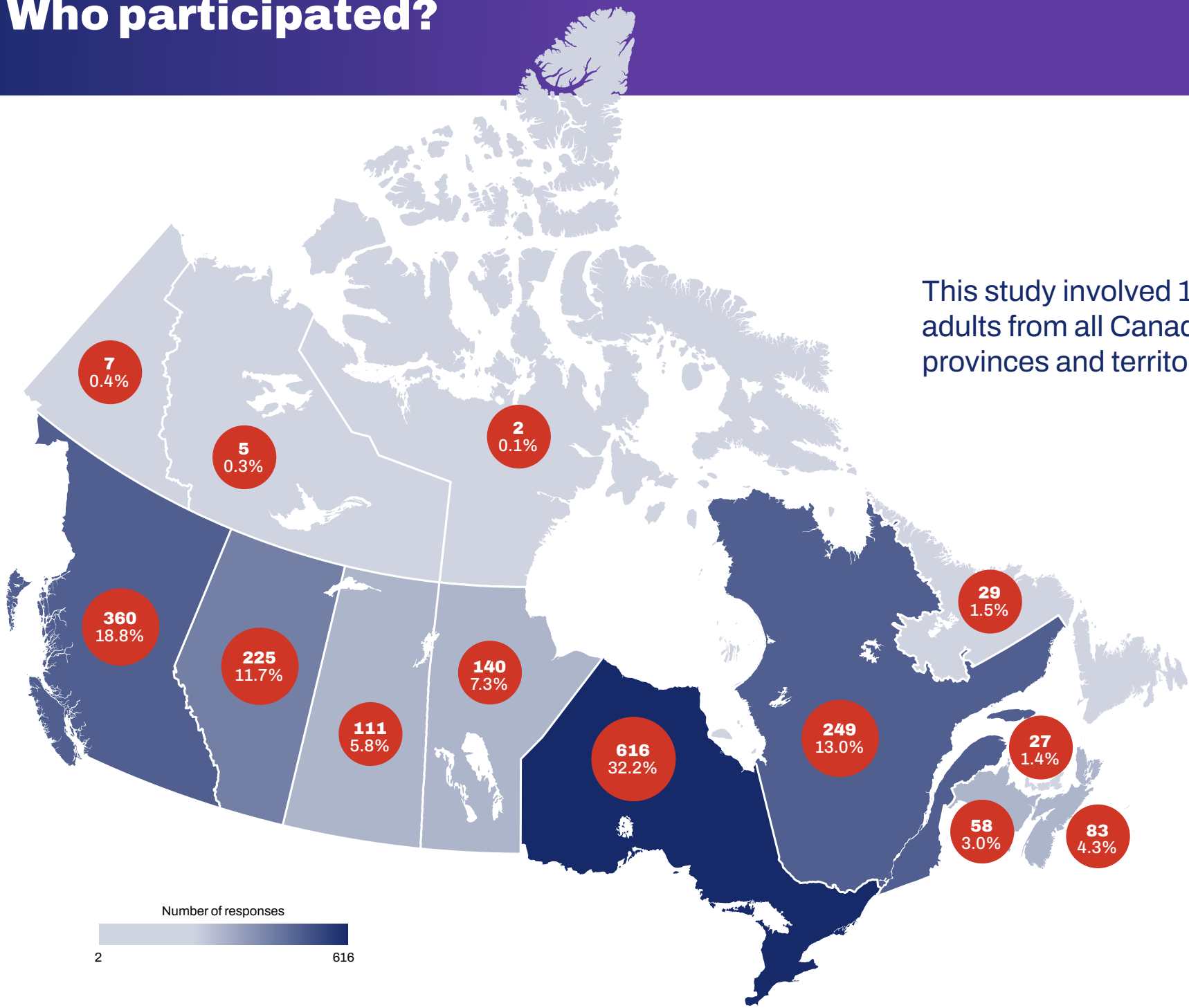
“ For a long time in Canada, Autistic people have not really had a say in the creation of policies meant to support them. With this survey, we have not only enabled Autistic adults to share their perspectives and needs to policymakers, but also do so in a way that was co-designed with members of the community to ensure that we asked the right questions, the right way. I am proud of that.”

— Dr. Mackenzie Salt

The researchers and advisory group designed the survey together so it would capture what Autistic people cared about. The final survey includes information about participants, such as their age, gender, and where they live, and sections focused on overall quality of life, functional abilities, and symptoms and challenges identified by participants.

To get more people from across the country to take part in the survey, we tapped Autism Alliance of Canada’s broad network, which includes over 800 individuals and member organizations. We also teamed up with 15 organizations that help Autistic adults, with some offering paper surveys to their communities. We also used targeted ads posted on social media, in online newsletters, and emails.

Who participated?

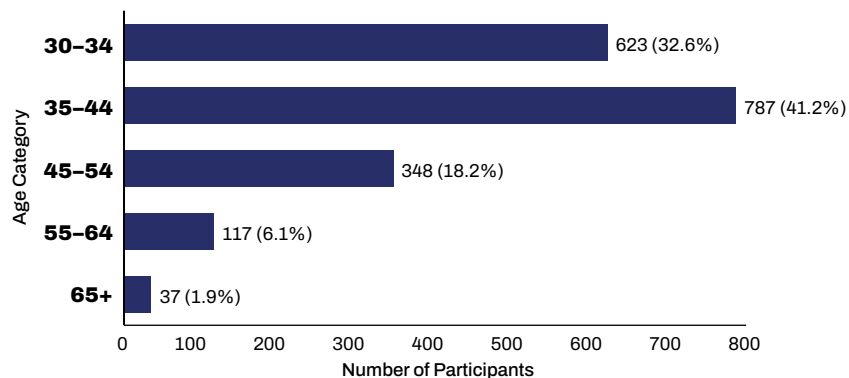


This study involved 1,912 adults from all Canadian provinces and territories.

Who participated? Cont'd

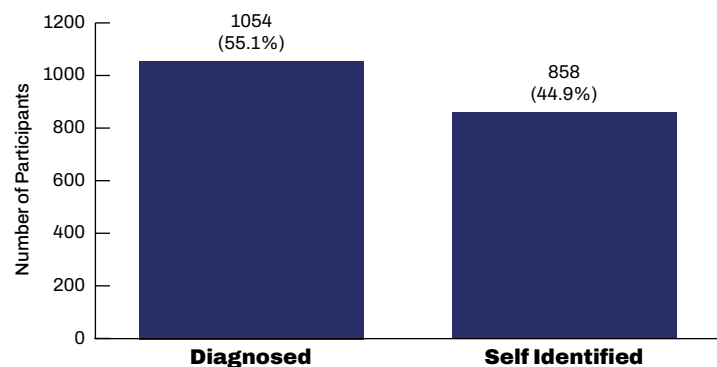
Number of Participants by Age Category

More than 25% of participants were 45 years old or older, and participants' ages ranged from 30 to 78 years old.



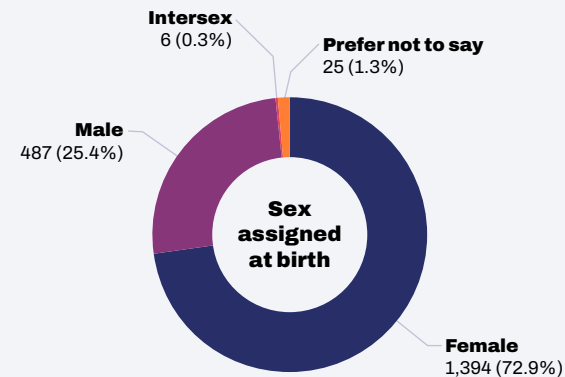
Diagnosed vs Self Identified Participants

We heard from people with formal autism diagnoses (i.e., given by medical professionals) and those who identify as Autistic but do not have a diagnosis in about equal numbers.

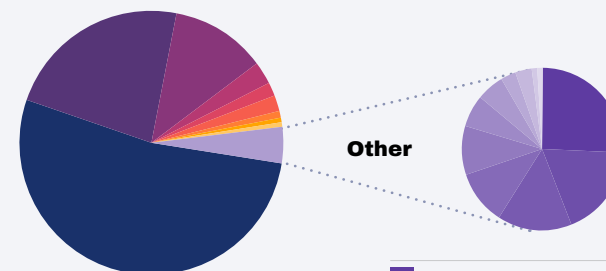


Sex assigned at birth and Gender identity

Three-quarters of the participants were assigned female, and one-quarter were assigned male at birth.



More than 20% of participants mentioned that their gender identity was different from cisgender.



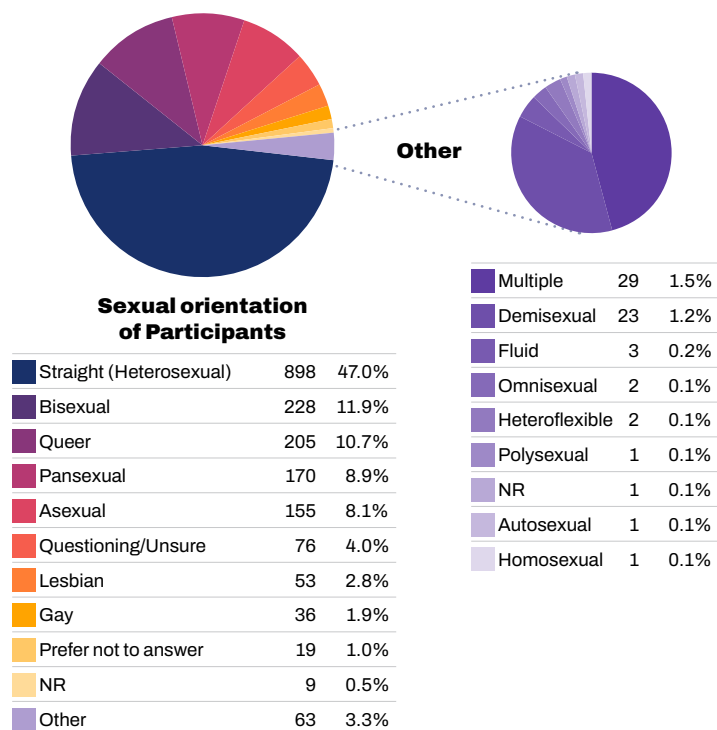
Gender Identities of Respondents		
Woman	1007	52.7%
Man	432	22.6%
Non-binary	224	11.7%
Genderfluid	51	2.7%
Questioning/Unsure	35	1.8%
Transgender man	35	1.8%
Transgender woman	14	0.7%
Prefer not to answer	11	0.6%
NR	10	0.5%
Two-spirit	9	0.5%
Other	84	4.4%

Other		
Agender	24	1.3%
Multiple	17	0.9%
Neurogender	14	0.7%
Genderqueer	10	0.5%
Demigender	6	0.3%
Bigender	5	0.3%
Gender Apathetic	3	0.2%
Transmasculine	3	0.2%
Pangender	1	0.1%
NR	1	0.1%

Who participated? Cont'd

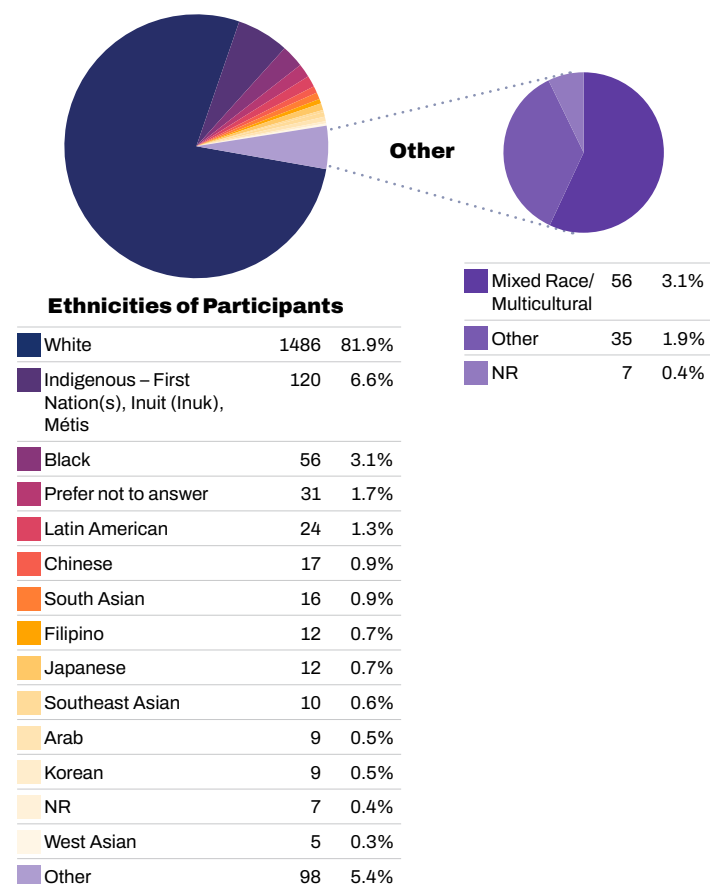
Sexual orientation

Almost half of the participants identified as something other than heterosexual.



Racial/Ethnic background

Most (78%) participants identified as White. Further, 6% identified as Indigenous, and more than a third of them reported residing on-reserve.

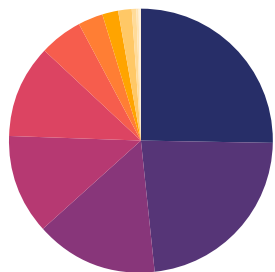


Who participated? Cont'd

Level of Education

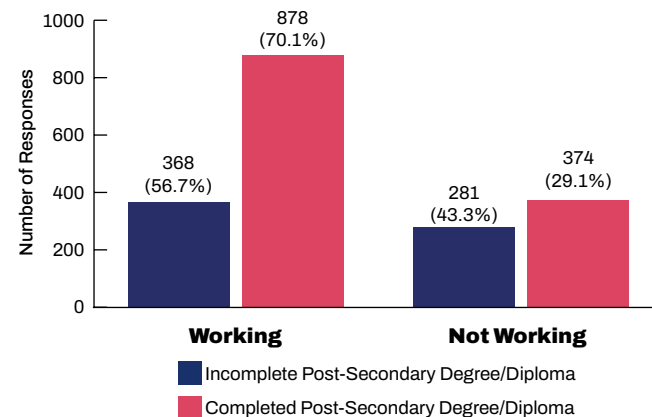
Almost two thirds of participants completed a college diploma or university degree at any level. Among those in the group who didn't begin or finish their postsecondary education, 57% have jobs compared to 43% who don't have jobs. Among those with a postsecondary education degree, 70% have jobs, while 30% are unemployed.

Highest Level of Education Completed of Participants



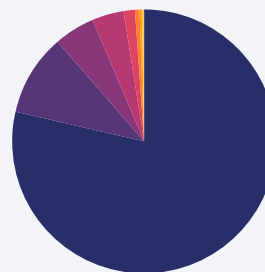
Bachelor's degree	487	25.5%	Doctorate	58	3.0%
College, technical school, or CEGEP diploma	438	22.9%	Professional degree	38	2.0%
Some post-secondary education	291	15.2%	Grade 8	30	1.6%
Master's degree	231	12.1%	Prefer not to answer	10	0.5%
High school or equivalent	220	11.5%	Other	7	0.4%
Some high school	99	5.2%	Grade 4	2	0.1%
			NR	1	0.1%

Employment Status of Participants based on Level of Education Completed



Communication

The primary communication method for 78.9% of respondents is verbal communication, indicating a lack of representation from non-verbal adults in this sample.

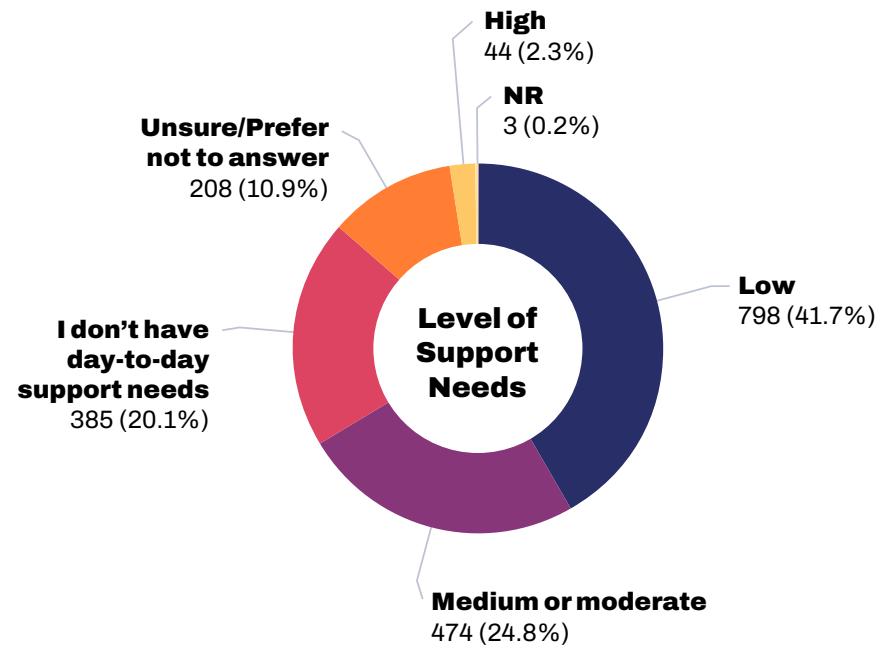


Primary Communication Mode

I speak verbally	79.0%
NR	10.0%
I communicate through writing.	5.0%
I have situational or selective mutism	3.9%
I use augmentative and alternative communication (AAC) (such as text-to-speech software, PECS, etc.)	1.2%
I use a sign language or a form of signed language	0.7%
I require a support person to be able to communicate.	0.3%
I use an alternate form of communication not listed. (Please specify)	0.1%

Who was missing

Despite our best efforts, some groups were not well represented in the survey. We heard from fewer Autistic adults with high support or communication needs, with low levels of education and employment, and from fewer people assigned male at birth. This affects how we understand the survey results. It's likely that the actual need among Autistic adults is even higher than what our findings show.



Key Findings: 7 Areas of Need

Autistic adults have different and complex needs throughout their lives, including healthcare, education, finance, and social connections. It's important to ensure that health and social care systems work well to meet the diverse needs of the community. Making these changes in the system needs everyone, from the government at all levels, to clinicians, service providers, organizations and to Autistic people and their families, to work together continuously and actively participate in decision-making.

Our survey identified **seven overarching areas of need:**

1 | Accessing Diagnosis

5 | Transportation

2 | Employment

6 | Health

3 | Financial status

7 | Social inclusion

4 | Housing

1 | Accessing Diagnosis

Getting a formal autism diagnosis in Canada is really hard for adults. Our results show that many adults identify as Autistic but do not have a diagnosis and would like to get a formal diagnosis if there weren't so many obstacles. Making it easier to get a diagnosis is very important. Our study and prior research [1] both point to the positive impacts of diagnosis on the lives of Autistic adults.

“ I was super excited to have an answer and a word that described me. A word meant that there are other people who know what it's like. That was major.”

— 52 year old Autistic woman

“ My diagnosis opened up an understanding that my entire family is probably autistic, and reframed many things that were previously sources of guilt, shame, or misunderstanding. It has also allowed me to start being more “open” with friends — I had internalized at an early age (due to bullying) that it was not safe to share my personal opinions or feelings with others, and my diagnosis allowed me to start questioning those assumptions.”

— 48 year old Autistic woman

- Almost 70% of those with a formal diagnosis felt that getting one had a positive impact on understanding their personal identity. Just over half of them also said it positively affected their mental health.
- Almost 80% of those who identified as Autistic but who did not have a formal diagnosis said they would get a diagnosis if there were no barriers to doing so.
- The most frequently reported challenge to getting a diagnosis in Canada was the cost.

[1] <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8727520/>

2 | Employment

Our survey shows that many Autistic adults in Canada face challenges finding jobs and getting enough support at work. The findings reveal that more than a third of participants are currently unemployed, which is very different from the low unemployment rates (under 20%) for Canadian women and men aged 25–54 in 2023 [1]. Education significantly impacts job opportunities, showing the need for comprehensive employment and education supports for Autistic adults to enhance their success and advancement throughout their career journey. To tackle this issue, Canadian policies should focus on giving thorough support for employment to Autistic adults throughout their careers, helping them succeed in various industries.



I am afraid to ask for accommodations due to fear of stigma, not being believed etc.”

— 30 year old Autistic woman



I have degrees in teaching and in law but working in those fields was extremely difficult and stressful as an undiagnosed autistic person. I didn't know at the time why I struggled. I left law very quickly to work an easier job and then stayed home after my first child was born.”

— 40 year old Autistic woman



I've had dozens of jobs, some high-profile, some menial. I've been able to keep none. I'm no longer in my 30s so being hired is impossible. Plus my resume is a hodgepodge and not the high-level, focused career paper expected by my age. I can't handle full-time hours. I can't really handle meetings in any form over 30 mins because I can't process what's being said, perform conversation, AND retain what I need to do all at the same time. I can't work in bright/loud/distracting environments. So the work I can do — which is a lot — is restricted by those external factors. Plus getting work relies on knowing people/relationships and I no longer have those.”

— 52 year old Autistic woman

- 70% of survey participants with a post-secondary degree have jobs, while only 55% of participants who have not completed a degree are employed.
- 55% of participants feel they don't have enough support to move forward in their jobs, and almost half don't have the support they need to do their current job.
- Less than 30% of participants reported using accommodations at work.

[1] <https://www150.statcan.gc.ca/n1/daily-quotidien/240105/dq240105a-eng.htm>

3 | Financial Status

Autistic adults are financially vulnerable. Many survey participants rely on government disability assistance. Unfortunately, they are not alone. Poverty is widely reported among people receiving provincial and territorial disability benefits **[1]**. The disability community as a whole eagerly awaits the arrival of the Canada Disability Benefit **[2]** and the security it could provide for changing levels of need across the lifespan. It's very important that future policies strongly prioritize providing solid financial support for this community across the country.

“ I never earned much income in any of the jobs I had. It negatively affects my future quality of life. Because I could not contribute more than the minimum amount of funds towards CPP and never had money to invest in an RRSP, my monthly OAS benefit will be (get this) \$600. (...) The CPP program is based on a purely earnings-based calculation which means the government treats it as a “you get out what you put in” benefit. That puts all low-income earners at an immediate disadvantage from the start since the dollars they are able to put in today will never be able to purchase the same amount of goods forty years from now.”

— 64 year old Autistic man

- A quarter of participants say they do not have enough money to buy what they need.
- More than half of participants have no retirement savings.
- More than 40% of participants lack any short-term savings.

[1] https://www.disabilitywithoutpoverty.ca/wp-content/uploads/2023/06/DWP-Report-Card-23-FINAL_compressed.pdf

[2] <https://www.disabilitywithoutpoverty.ca/publications/the-benefit>

4 | Housing

Canada's housing affordability crunch affects Autistic adults at much higher rates than the general population. The survey data show that more Autistic adults spend more than the recommended 30% of their income on housing than the general population **[1]**, and often for less-than ideal living situations. Housing policies should focus on giving more financial help and different housing options for this community.

“ I desperately need my own place. My current room in my parent’s house is very small, and there’s barely any room to stand as this very small space is packed with all of my worldly possessions. I have saved up enough money to be able to move out, but I am really reeeeeaaaaally struggling getting the home buying process started due to all the social interaction involved. I will try for hours to psych myself up to contact a mortgage broker or bank, but I always chicken out. I am too ashamed to ask for help.”

—32 year old Autistic woman

“ I live in social public housing that is subsidized based on my government assistance and part time earnings. As an autistic/ disabled individual I would not be able to afford market value housing, I require subsidized housing.”

— 47 year old Autistic man

- More than a third of participants report living in inadequate housing or living situations that don't fully meet their needs.
- Close to 70% stated their housing costs consume 30% or more of their monthly income, or that someone else is covering these costs. Statistics Canada figures **[2]** show that only 14.8% of Canadian homeowners and 33.2% of Canadian renters spent on housing at that level in 2020–21.

[1,2] https://www150.statcan.gc.ca/n1/en/subjects/housing/housing_costs_and_affordability

5 | Transportation

Many Autistic adults find it challenging to move around their community independently. Improving mobility and independence through policy [1] more generally is a goal supported by the larger disability community. Changes at the provincial/territorial, federal, and municipal levels are needed to encourage independent travel for Autistic adults and others.

“ I can’t always drive and don’t know when that will be. Sometimes I’m exhausted. Sometimes my senses are on 100 and even dark glasses won’t work. Sometimes I’m too distracted by everything on the road. Other times, perfectly fine. Enjoyable even. So if I make appointments, who knows?”

—52 year old Autistic woman

“ I find public transportation very stressful. The noise of lots of people talking causes me to mentally shut myself in. If my car breaks down, I will opt to not go out anywhere rather than take a bus or train. Travelling larger distances, such as by plane, requires an excessive amount of mental preparation, and I require a huge solitary recovery period upon arrival.”

—49 year old Autistic woman

- 35% of participants rely mainly on others or shared transportation to navigate in their communities.
- More than 20% of participants found it somewhat or very difficult to get around their communities.
- Nearly half of participants who did not find it easy to get around their communities mentioned being unable to drive for various reasons.

[1] <http://www.ccdonline.ca/en/transportation/>

6 | Health

Autistic adults face various physical and mental health challenges [1], including co-occurring conditions [2]. The majority of survey participants rated their mental health as fair or poor, and almost half rated their physical health similarly. Even though these challenges affect their daily lives, many participants said they couldn't get treatments that worked for them, or at all. It is crucial to have policies that remove obstacles to Autism-informed care for Autistic adults to thrive.

“Executive function governs most everything so even if physically I'm good on a day, I might not be able to take advantage of it. Or on a good day, I might spend all my time catching up from the 3 down days before.”

—52 year old Autistic woman

“I feel my health, both physical, and emotional/mental has been extremely mismanaged/neglected most of my life until I found the right words to describe what I was experiencing. And even then it becomes a battle of being believed, or shrugged off.”

—40 year old genderfluid Autistic person

- Over 40% of participants mentioned having more than 5 types of chronic conditions.
- Only one third of participants said they can mostly or fully do things they like because of their health.
- More than half of participants don't have enough access to a regular health care provider for their physical health.
- Over 70% of participants don't have sufficient access to mental health services.

[1] <https://ijmhs.biomedcentral.com/articles/10.1186/s13033-023-00587-6>

[2] <https://bcmj.org/articles/autism-current-practices-and-controversies>

7 | Social Inclusion

Making sure Autistic adults feel included in society is very important for their overall well-being. Feeling socially disconnected can lead to various health risks, like dementia and heart disease **[1]**. Aligning autism policy with the Accessible Canada Act **[2]** can help remove barriers and create an environment that welcomes and accepts Autistic adults. It's crucial for society to recognize and celebrate the unique strengths and perspectives of Autistic adults, in order to foster a culture of diversity, acceptance, and inclusivity.

“ I have zero friends. I have had work acquaintances, but we only ever talked while at work, any attempt to meet up after work was never followed through on. Once I left that job those acquaintances were also left behind. I would like to have friends, I'm just not sure how.”

—42 year old Autistic man

“ I have learned to blend in socially. However, I feel very alone. I am not able to be myself with anyone (even my close friends) and am socially anxious all of the time. I want to have more close relationships. My struggle in group situations makes it harder to start building relationships as usually the first place you meet people is in a group setting. Connection with others is very important to me.”

— 39 year old Autistic woman

- Almost 90% of survey participants said they've felt left out or isolated, which is more than double the rate among Canadians during the pandemic **[3]**.
- Almost 45% of participants were dissatisfied or very dissatisfied with their social activities.

[1] <https://www.cdc.gov/aging/publications/features/lonely-older-adults.html>

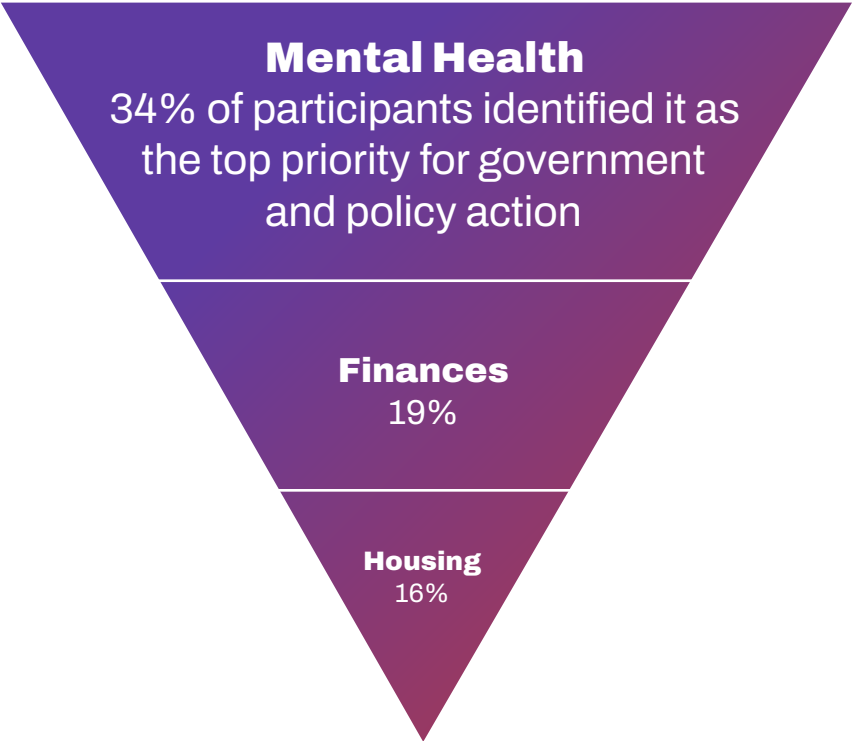
[2] <https://laws-lois.justice.gc.ca/eng/acts/a-0.6/>

[3] <https://www150.statcan.gc.ca/n1/daily-quotidien/211124/dq211124e-eng.htm>

Priority Setting

Survey participants were also asked to tell us what areas in life they think the government should focus on and where research efforts should be directed. Their thoughts are essential for shaping future work in research and policy, specifically addressing the priorities identified by the Autistic community. Here's what we discovered:

Top priorities for the government to address in policy



Top priorities for research



Where do we go from here?

Our findings underscore the significant challenges faced by Autistic adults in Canada, revealing a range of pressing needs across various aspects of life. To effectively address these, the Canadian government must collaborate across sectors, involving Autistic people, their caregivers, families, and those with lived experience in decision-making. The existing system requires significant transformation, with a comprehensive approach needed to better support Autistic people throughout their lifespan.

In Canada, ensuring that systems work effectively for Autistic people and their loved ones requires a complete approach across multiple domains. Effective solutions require addressing the diagnostic process, ensuring standardized pathways to reduce disparities in access and care. For adults, the lack of established pathways to diagnosis creates significant barriers, leaving many without access to essential support services. This absence of system capacity not only hampers timely diagnosis but also perpetuates a two-tiered healthcare system, where autistic adults are forced to pay out-of-pocket for services that should be covered under our healthcare act. By failing to address this critical gap, we are violating the principles of equitable access and perpetuating systemic injustices for Autistic people. Addressing these gaps in the diagnostic process is essential to uphold the principles of inclusivity and ensure that Autistic people receive the support they rightfully deserve under our healthcare system.

Inclusive and supportive educational practices, from primary to post-secondary education and into employment, are essential. Adaptations in the workforce landscape, inclusive hiring practices, and robust organizational support are necessary to accommodate neurodiverse individuals. Additionally, inclusive and accessible housing is fundamental for Autistic people to thrive independently in their communities.

A National Autism Strategy serves as a crucial tool in addressing the diverse needs of Autistic adults and bridging the disparities in services among provinces and territories. By establishing a cohesive framework at the national level, it facilitates collaboration and coordination between different jurisdictions, ensuring that Autistic people receive equitable access to services and support regardless of where they reside. National strategies provide a roadmap for governments to prioritize key areas such as diagnostic pathways, education, employment, and housing, enabling the development of standardized policies and interventions tailored to the unique needs of Autistic people across the country. Moreover, they facilitate the pooling of resources and expertise, fostering innovation and best practices that can be scaled and implemented nationwide, ultimately fostering a more inclusive and supportive environment for Autistic Canadians.

As champions for the rights and well-being of Autistic people, Autism Alliance of Canada remains steadfast in our commitment to driving forward the development and enhancement of a National Autism Strategy. Leveraging the insights gleaned from our survey findings, we have developed a set of evidence-informed recommendations. Aligned with our mission, these recommendations are poised to pave the way towards a brighter, more inclusive future for Autistic Canadians and their families. Together, let us continue our journey towards a Canada where every Autistic person is valued, supported, and empowered to thrive.

A National Autism Strategy Should Include:

Equitable Access to Services Across the Lifespan, Including Adulthood: Include ways to ensure that adults can get screened and diagnosed for autism in a timely, fair, and affordable manner through our publicly funded health care system. A NAS should include support to increase the capacity of community care providers to diagnose autism and connect Autistic adults to post-diagnostic supports, using a stepped-up-care approach.

Economical Inclusion: Include ways to help Autistic adults be more involved in the economy. Especially, focus on federal funding for programs that let individuals manage their own cases, with a focus on education and employment. Start these programs in secondary school, continue through the transition to the workforce, and throughout their lives.

Financial Stability: Include ways to give more financial support to Autistic adults by making it easier for them to get help from disability support programs, programs that help them join the job market more, and access income and benefit programs.

Accessible and Affordable Housing: Work together with the National Housing Strategy and the Disability Inclusion Action Plan to solve the immediate and long-term housing crisis for Autistic adults. A NAS should also increase the availability of affordable and inclusive housing for Autistic adults through agreements and funding. Additionally, it should tell federal agencies and departments responsible for housing to include Autistic people in decision-making and investment strategies, following a right-based approach.

Inclusive Transportation Regulations: Coordinate with the Ministry of Transportation to make sure disability regulations take autism and other invisible disabilities into account in regulatory design.

Knowledge Sharing: A NAS should also create a learning network for practitioners and policymakers to gather evidence and agree on best practices and policy changes across the country.

Integrated Support for Autistic Adults: Invest in building integrated systems to support Autistic adults. This includes creating a strong, flexible, and neuro-inclusive system to address their complex physical and mental health needs. Additionally, a NAS should work on improving access to healthcare providers and mental health services by collaborating with provinces and territories. The strategy should also offer accessible resources and specialized training for primary care and mental health providers.

Building Autistic Adult Support: Invest in building capacity and social infrastructure for the adult Autistic population in communities. A NAS should also address the inconsistencies in the application of accessibility standards across federal, provincial/territorial levels of government.

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Research Team

This project was led by Dr. Mackenzie Salt, who is a postdoctoral Health System Impact Fellow with the Canadian Institutes of Health Research (CIHR). Dr. Salt is an expert in research focused on and involving Autistic adults. He is also an Autistic adult himself, which means he has personal experience and a unique viewpoint when working on research and collaborating with the Autistic community.

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