# Snapshot

## Why we did this

Autism Alliance of Canada worked with the Public Health Agency of Canada (PHAC) to run a national survey called "<u>Fostering Inclusion: Exploring the</u> <u>Needs of Autistic Adults in Canada.</u>" The survey looked at important areas like health, housing, transportation, jobs, money, and access to services. **Survey participants said their top two priorities were mental health and social connections.** 

The Autism Alliance of Canada research team partnered with the Sinneave Family Foundation and McMaster University to start Phase 2 of the project. We held focus groups with Autistic adults in Canada to understand these needs better. This summary shares "a snapshot" of what they found about mental health, social support, and the barriers Autistic adults face in getting services. It also includes recommendations from participants on how to address these issues.

## What we did

This project included 12 online focus group discussions with Autistic adults from across Canada. In these discussions, we asked about the mental health and social support services these Autistic adults needed and talked about the barriers they faced when trying to access existing services. Together, we created recommendations on how to solve these problems. Focus groups were chosen so that Autistic people could share their experiences and needs in their own words.

## What we found

#### Who participated

The focus groups for this study included 64 Autistic adults, with about 70% of them between 30 and 45 years old. Participants came from eight provinces across Canada, with most from Ontario and British Columbia. Almost two-thirds of the group had a formal autism diagnosis, while the rest self-identified as Autistic. The group included people from different gender identities, with strong representation from gender-diverse people.

Most participants had a higher level of education than secondary school, spoke English, and were White, with a few identifying as mixed ethnicity. The study didn't reach people who only speak French or non-speaking Autistic adults, which is important for future research to make sure all voices are included. Although the study highlights the many challenges Autistic adults face, the actual level of need may be even higher than reported because of the specific group who participated in the study.







#### **Key Findings**

There are major gaps and barriers in mental health and social services for Autistic adults in Canada. While this might not be surprising to those who work in autism services or have lived experiences, it's important because these insights come directly from Autistic adults themselves. When looking at services from a broad perspective, it's easy to overlook the real experiences of individuals. This project sheds light on those personal experiences.

The gaps identified include a lack of mental health care focused on adults, not enough practitioners who understand autism, and unavailable diagnostic services. Autistic people struggle to access important services due to long wait times, confusing paperwork, and few affordable options, especially in rural areas. Social support systems are also lacking, with few community programs, limited job support, and not enough initiatives led by Autistic people. Also awareness and acceptance of autism in society are low, and those with intersecting identities face even more challenges. This report includes recommendations based on input from Autistic adults to improve services and reduce barriers. The Autism Alliance policy and research team adapted these suggestions to propose specific actions that can be taken by Autistics, service providers, governments, researchers, and community organizations. These actions aim to improve services, make them more accessible, and enhance the inclusion of Autistic adults in society.

### Where do we go from here?

Moving forward, addressing the gaps in services for Autistic adults needs urgent attention and resources. Recommendations from Autistic adults themselves emphasize the expansion of adult-focused autism services, particularly in mental health and employment supports, alongside better financial assistance and greater social support networks. There is also a pressing need for inclusive pathways to care that do not solely rely on family physicians or a formal diagnosis. Public funding and access to affordable services as well as targeted support for caregivers and families are critical to alleviate existing barriers. Implementing these measures will significantly improve the quality of life for Autistic adults and create more equitable systems.

Equally important is the need for Autistic people to play an active role in the design and evaluation of the services that impact their lives. Establishing lived experience committees, diversifying service providers, and fostering collaboration across government, civil society, and the Autistic community are key steps toward long-term, sustainable change. This inclusive approach can enhance public awareness, reduce stigma, and ensure that supports are informed by those who use them. By working together, we can build more accessible, compassionate, and effective support systems for Autistic adults in Canada.

## Want to know more?

If you would like to know more about this project and its findings, access our full public report here.

Further, explore the infographics below for visual summaries of our results.

- Infographic <u>Mental Health Services</u>
- Infographic <u>Community-Based Social Supports</u>
- Infographic <u>Recommendations</u>