



Summary Report

Autism in Canada: Considerations for future public policy development

Weaving together evidence and lived experience



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Canadian Academy of Health Sciences

Autism in Canada

*Autism*¹ is a neurodevelopmental condition that impacts individuals across the lifespan. There is diversity in how this condition presents and evolves over time. *Neurodiversity* describes autism as a condition or identity rather than a disorder. This line of thinking reflects a more neutral framing of the neurological differences inherent to autism. Many Autistic individuals and their families face social and economic barriers that affect their quality of life. Co-occurring conditions also introduce further complexities and challenges.

About 1 in every 50 (2%) Canadian children and adolescents is autistic, according to the Public Health Agency of Canada. This rate has continued to increase over time. Less is known about how many Autistic adults there are in Canada.

The Assessment on Autism

Over a 19-month period, the Canadian Academy of Health Sciences conducted an arms-length Assessment on Autism on the themes of Diversity, Social Inclusion, Diagnosis, Supports, and Services, and Economic Inclusion.

The assessment involved a comprehensive evidence review and pan-Canadian stakeholder consultation. Guided by shared expertise, the assessment concentrated on what could be learned from research evidence and stakeholders about how to better serve and support Autistic Canadians and their families. This assessment culminated in the report: [Autism in Canada: Considerations for future public policy development](#).

Themes

Intersectionality and Diversity

Autism intersects with other identities such as race, ethnicity, culture, socioeconomic status, gender, and sexuality. This *intersectionality* creates diversity in experiences and needs.

Research about the diversity of Autistic people in Canada is limited. But, it is known that they face additional and unique barriers especially if they live in rural and remote areas or are part of *equity-seeking groups*. At the same time, there are opportunities to build on the strengths of this diversity.

¹ All teal, italicized terms can be found in the glossary at the end of this Summary Report.

Approaches developed in partnership with equity-seeking groups, such as Indigenous and *racialized people*, can help better meet their needs and build on their strengths. Indigenous-led, culturally-relevant, and localized approaches to supporting Autistic people are central to respecting, recognizing, and addressing the distinct experiences of Canada's First Nations, Métis, and Inuit peoples. Traditional and cultural Indigenous practices could also offer valuable contributions to our understanding of *inclusion* and supports and services that may benefit all Autistic people.

Social Inclusion

Social inclusion is an integral aspect of wellbeing and quality of life for all Canadians. Inclusive communities for Autistic people offer belonging, acceptance, meaningful participation, and emotional and physical safety. They also provide equitable access and accessibility to resources and opportunities.

Addressing Discrimination and Promoting Autism Acceptance

Autistic people do not always feel safe or meaningfully included in their communities. Such experiences can have harmful outcomes to their health, safety, and quality of life.

Stigma and discrimination can be addressed by shifting public attitudes towards *autism acceptance* and awareness through public campaigns, social contact, training, and education programs. Sometimes Autistic people need increased support to make decisions about their lives. It is important that this decision-making support does not place them at risk for financial abuse or neglect. It should promote dignity and maximize autonomy as much as possible.

Physical and Emotional Safety

Physical and emotional safety can be fostered by promoting autism-inclusive, *neuro-affirming*, and accessible spaces, programs, and understanding in local communities. Collaborative service delivery and specialized training amongst public safety personnel and mental health providers may improve crisis interactions and outcomes. Best practices for suicide prevention can also be adapted to better meet the needs of Autistic individuals at risk for suicide.

Promoting Community Participation

Improving the accessibility and inclusion of public transportation, recreational facilities, leisure programs, and technology can enable community participation of Autistic people. These improvements can occur through planning, infrastructure, localized needs assessments, and staff development. Other promising practices include skill-building techniques and providing autism-specific *accommodations* and supports.

Diagnosis, Supports, and Services

Equitable Access

Each province and territory offers autism diagnostic and support services. Yet, there is wide variability in what is available which can contribute to delays and disparities. Some Autistic people are particularly disadvantaged, such as those living in rural and remote areas, equity-seeking groups, and Autistic adults.

Addressing these systems gaps could be supported through *capacity building* of a diverse and skilled autism workforce, expansion of tele- and e-health, and enhanced navigation services. Other jurisdictions have also implemented national clinical autism guidelines or consensus statements, safety standards, and increased transparency regarding wait times.

Recognition and Diagnosis

It can take months or years for a child to access a publicly-funded diagnostic assessment for autism. These assessments may not be available in adulthood. A stepped approach can address such barriers. In a stepped approach, first a primary care physician is consulted. If the diagnosis is too complicated or they do not have the skills, either a specialist or diagnostic team would become involved. Research to develop valid and meaningful, strengths-based diagnostic tools and improve access to diagnostic assessments for Autistic adults is also suggested.

Families

The responsibilities of supporting an Autistic individual within a complex and fragmented system can affect all *family members*. Adopting family-centred services available across the lifespan can promote the health and wellbeing of the entire family. It also empowers families to be involved in service delivery.

Autism Supports and Services

Early Childhood Supports and Services

Young Autistic children benefit from early access to supports and services because this is a time of significant development. A stepped service approach can be helpful. This approach is needs-based, rather than constrained by diagnosis or to a single intervention. It is driven by assessments of the child's needs (e.g., in terms of service type, amount, and duration) in the context of their family and culture.

Effective early intervention approaches:

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- Are of needs-based intensity and duration,
 - Are provided with fidelity by skilled *service providers* in and across multiple community settings,
 - Promote family participation and integration into daily life, and
 - Are accompanied by continuous and rigorous evaluation of child- and family-oriented outcomes.
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Naturalistic developmental behavioural interventions (NDBI) can exemplify these principles. Early intervention services can be offered across multiple settings, including early learning and childcare settings and the home.

School-Aged Supports and Services

Equitable access to school and community supports across a range of life domains can promote academic success, life and social skills, and improve mental health. Peer acceptance and inclusion programs can also help prevent bullying and other forms of exclusion.

Transition to and through Adulthood Supports and Services

Leaving secondary school represents one of life's most significant transitions. It can be a challenging time for Autistic individuals as services and supports end with few comparable options available for Autistic adults.

Implementing health and education transition policies and practices may help manage and prevent mental and physical health challenges and promote better adult outcomes. However, research about autism in adulthood is limited. For example, not a lot is known about the support needs of Autistic parents and the growing population of older Autistic people.

Economic Inclusion

Economic inclusion involves removing barriers to financial stability, managing autism-related costs, and maintaining meaningful employment. It also involves the impacts of financial instability over time on individual and family wellbeing.

More than half of Autistic Canadians rely on disability benefits. Financial stability can be supported by reforming access to benefit and tax credit programs, offsetting common out-of-pocket costs, and making sure that resources are available to support Autistic persons and their families in managing money and planning for the future. Offering flexible income and/or medical benefits and encouraging job participation through more flexible disability policies may also promote more stable employment pathways.

Labour market participation of parents of Autistic individuals benefits the entire family. It can be supported through workplace policies and provisions offered through unions, employee assistance plans, and human resources.

Post-Secondary Education Pathways

With appropriate supports, many Autistic individuals can participate in post-secondary education, but they are still not enrolling to the same extent as non-autistic and other disabled students. Available academic supports and accommodations do not always meet the diverse range of Autistic students' needs and abilities.

Autism-specific programs offer a combination of supports such as transition services, residence life planning, peer mentoring and support groups, tutoring, academic accommodations and counselling, and *life skills* coaching. While such programs are offered in the United States, few exist in Canada.

Post-secondary costs can be prohibitive for Autistic students. Allowing for more flexible tuition requirements that consider the extra time needed by some Autistic students to complete their degrees can help decrease these costs. Autistic students can also benefit from enhanced access to internships, cooperative education, and campus employment services.

Employment Opportunities

Despite many Autistic people wanting to work, many are not included in the labour market. There are societal benefits of inclusive workplaces and Autistic workers' contributions. Some ways to create more inclusive workplaces and improve employment outcomes can involve:

- Providing autism-inclusive employment supports and accommodations by knowledgeable providers,
- Access to supported work experience and internships,
- Addressing benefit disincentives, and
- Promoting workplace autism acceptance.

Autism-Inclusive Housing Solutions

With the limited availability of affordable housing in many regions, autism-inclusive housing is in even shorter supply across Canada. The need is only expected to grow. Autistic individuals without co-occurring *intellectual disability* or physical impairments may not be prioritized or eligible for supportive or affordable housing. Autism-inclusive or friendly housing means residential spaces and models that consider the unique needs of Autistic people within the design, layout, activities, geographic location, and where necessary, staffing complement and access to other community supports, such as mental health services. The accessibility of affordable housing often does not consider modifications relevant to many Autistic people.

Improving housing supply and adequacy could include:

- Adopting person-centred planning and skill acquisition approaches,
- Designing and scaling up autism-inclusive housing models,
- Addressing waitlists and eligibility,
- Hiring skilled support staff,
- Offering nearby or linked community supports, such as access to mental health services,
- Engaging in long-term planning with individuals and families, and
- Proactive social and community planning.

Positioning for Impact

Data collection and sharing, research, and collaboration are key enablers for system improvement. To obtain more meaningful knowledge, the data on autism diagnosis rates needs to be linked to information about service use and health and wellbeing outcomes. It is only through a new data sharing infrastructure that such valuable information can be produced.

Most autism research has focused on causes, prevention, and characterization in childhood. This research offers important insights, but overlooks many of the day-to-day needs and priorities of Autistic individuals and their families across the lifespan.

Strategies to improve future autism research include:

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- Balancing research across multiple areas and disciplines of research, including clinical, systems, biological, and social sciences,
 - Alignment to the priorities and needs of Autistic people and their families,
 - Recruiting diverse Autistic collaborators, researchers, and participants,
 - Longitudinal designs about changes over the lifespan,
 - Cross-sectoral research by transdisciplinary teams,
 - Focusing on service delivery, quality improvement, workforce capacity, and systems-level program evaluations,
 - Translational efforts from research to practice, and
 - Building capacity of autism researchers, including Autistic researchers.
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Conclusion

This assessment highlighted the breadth and complexity of needs of Autistic people and their families. Sustainable and efficient health and social care systems can flexibly address the broad range of needs of this growing population. Such system change is likely only possible through ongoing collaboration amongst all levels of government and Autistic people and their families.

Glossary

Here are some definitions of important words. The definitions are organized into two groups: Autism Words and Other Words.

Autism Words

Autism	<p>Autistic people’s brains work differently. Autistic people communicate and connect with other people differently. Autistic people may be overwhelmed by sensations such as loud noises and bright lights, but may really like other sensations. Autistic people may also benefit from certain routines or predictability and may focus intensely on certain interests.</p> <p>Autistic people often have other physical, intellectual, learning or mental health challenges or conditions.</p>
Autism acceptance	<p>Embracing autism in a <i>neuro-affirming</i> way—as a difference, not a disorder. Autism acceptance involves:</p> <ul style="list-style-type: none">• Developing an understanding of Autistic people’s ways of being, thinking and doing, and recognizing those ways as valid, and• Accepting and embracing Autistic people’s differences in all aspects of society. <p>Autism acceptance works to change public attitudes and behaviours towards Autistic people.</p>

Other Words

Accommodations	<p>Supports or services that help a person to function effectively in an environment or situation. For example, classroom accommodations for an Autistic student might include: a quiet place to work, visual cues, such as photographs to illustrate instructions, and routines that are clear and consistent.</p>
Built environment	<p>Human-made physical structures that make up the spaces where we live, learn, work, and play. These include, for example: homes, schools, workplaces, businesses, transportation, green spaces, and streets. The built environment can impact the health and wellbeing of individuals and whole communities.</p>

<p>Capacity building</p>	<p>Getting better at doing something and at adapting to change. Individuals can build their capacity and so can groups.</p> <ul style="list-style-type: none"> • Individuals build capacity by advancing their knowledge and skills. • Organizations and whole sectors build capacity by improving their systems—for example, by designing effective policies, providing and using resources well, and developing strong community partnerships.
<p>Developmental disability</p>	<p>A significant limitation in a person’s ability to develop skills for daily living, socializing, and learning. Developmental disabilities start before the age of 18 and continue throughout a person’s life. They affect thinking and doing.</p> <ul style="list-style-type: none"> • <i>Thinking</i> includes reasoning, organizing, planning, making judgements, and anticipating consequences. • <i>Doing</i> includes learning and applying various daily living skills. <p>In Canada, developmental disability is an administrative term applied to individuals who are eligible for provincial or territorial developmental services, such as respite and residential services. To meet eligibility, a combination of impairment in intellectual quotient and adaptive functioning is required.</p> <p>The United Kingdom uses the term learning disability in place of developmental disability. We have used the term intellectual disability rather than developmental disability in this report.</p> <p>An intellectual disability is different from a learning disability or difference. Learning disabilities may include dyslexia or dyscalculia. Many, but not all Autistic people have an intellectual disability or a learning disability.</p>
<p>Equity-seeking groups</p>	<p>Communities that experience barriers to full participation in society. The barriers are systemic, meaning that they are built in and widespread. Attitudes, social norms, the <i>built environment</i>, and other factors can all create barriers for groups of people.</p> <p>Seeking equity is different from seeking equality. Equality means everybody gets the same thing; equity means everybody is treated fairly, based on their needs and abilities. Because different groups face different barriers, achieving equity will require different supports and resources.</p>

<p>Family member</p>	<p>A parent/guardian, grandparent, sibling, spouse, or other non-paid <i>supporter</i> of an Autistic person. We use this broad understanding of family because defining “who is family” is deeply personal and cultural.</p> <p>We use the term parent when we are referring specifically to that relationship.</p> <p>Unless otherwise specified, a family member may be an Autistic person or a non-autistic person. For example, we sometimes differentiate between an Autistic parent and a non-autistic parent. An Autistic parent is a parent who is autistic.</p>
<p>Inclusion</p>	<p>A commitment to recognize and consider the needs and interests of Autistic people so that they are actively engaged in their communities. Inclusion goes beyond integration. With integration, the commitment is simply to have Autistic people present in the same space as non-autistic people.</p>
<p>Intellectual disability</p>	<p>Refers to significant impairments in both intellectual and adaptive functioning. In this report, we have primarily used the term intellectual disability rather than <i>developmental disability</i>. Some Autistic people have a co-occurring intellectual disability.</p>
<p>Intersectionality</p>	<p>The idea that:</p> <ul style="list-style-type: none"> • An individual has many identities, and • These identities interact in complex ways to affect one’s experience of advantage or disadvantage in the world. <p>The concept of intersectionality provides a deeper understanding of the barriers that Autistic people face. Race*, culture, socio-economic status, gender, sexual orientation, age, ability, and other identities can compound the advantages and barriers that Autistic people experience.</p> <p>*See also <i>racialized people</i>.</p>
<p>Life skills</p>	<p>Abilities that people need to manage and adapt to daily demands and challenges. These abilities include:</p> <ul style="list-style-type: none"> • Cognitive skills (such as decision-making, problem-solving, creative thinking, and critical thinking) • Emotional skills (such as self-awareness and self-management), and • Communication and interpersonal skills (such as relationship skills, communication, and social awareness).

Neuro-affirming	<p>An approach to interacting with Autistic and other neurodiverse individuals that:</p> <ul style="list-style-type: none"> • Accepts, understands, values, and celebrates <i>neurodiversity</i>, and • Does not try to fix different ways of thinking and being, or consider those differences to be illnesses.
Neurodiversity	<p>An understanding that brain differences among people are a natural and valuable part of human diversity.</p>
Racialized people, communities, groups, youth, or families	<p>People who face systemic disadvantages because they are not white. We use the term racialized rather than “visible minority” or “person of colour” to acknowledge that characterizing and discriminating against people in this way comes from the society; the problem is not rooted in the people themselves.</p>
Service provider	<p>An individual or group who is paid to provide a service that supports Autistic people. For example, a service provider might provide health, education, social services, or employment support.</p>
Supporters	<p>People who play important roles in an Autistic person's life and provide support in various ways. Supporters can include family members, friends, other Autistic people, allies, and neighbours, as well as people who are paid, such as service providers and support workers.</p> <p>Many people prefer the term “supporters” rather than “caregivers.” In our report, we tried to be specific whenever possible—for example, specifying “Autistic people’s families”, “service provider,” or “friends.”</p>