Autism Alliance of Canada
2021 Policy Compendium:
Social Inclusion, Diagnosis, supports, and services, & Economic Inclusion

Executive Summary

Introduction

In 2020-2021, the Public Health Agency of Canada (PHAC) requested the Canadian Academy of Health Sciences (CAHS) to conduct research and develop its now-published assessment report on autism.[1] Their work and report was aimed at summarizing the evidence on wide-ranging issues and topics relevant for developing a comprehensive National Autism Strategy (NAS), and was organized under three themes: social inclusion; diagnosis, supports, and services; and economic inclusion. In 2021, in parallel with the CAHS work and prior to publication of its report, the Autism Alliance of Canada (at that time named the Canadian Autism Spectrum Disorder Alliance, or Autism Alliance of Canada) developed a set of policy briefs to provide an early source of actionable policy recommendations for PHAC to address issues in these three areas. This resulting *Autism Alliance of Canada 2021 Policy Compendium*, presented here, was intended to supplement the thorough, but less recommendation-focussed, CAHS report. Similar to our prior *Autism Alliance of Canada 2020 Policy Compendium*, this policy compendium work was funded by Kids Brain Health Network (KBHN). Three multi-disciplinary working groups were struck, comprising researchers, professionals, students, Autistic advocates and other stakeholders from across Canada. Each group was led by one Autism Alliance of Canada-KBHN policy fellow. Working group members met monthly from June to November 2021, participating in a structured timetable of facilitated discussions, the goal of which was to develop three sets of focussed policy briefs. The aim of these briefs is to aid and support the federal government in taking actionable and effective steps in its early work to implement Canada's NAS.

Social Inclusion

Three briefs were developed within the theme of Social Inclusion. The first was aimed at addressing the inconsistencies in the application of accessibility standards across federal and provincial-territorial levels of government and organizations. It includes three recommendations: to extend federal accessibility legislation to private-sector organizations across Canada; to build federal-provincial-territorial partnerships to streamline accessibility standards; and to identify shared social inclusion indicators and promptly report on the findings to monitor progress of social inclusion. The second brief was aimed at breaking down physical and communication

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[1] Canadian Academy of Health Sciences. (2022). Autism in Canada: Considerations for future public policy development - Weaving together evidence and lived experience. Ottawa (ON): The Oversight Panel on the Assessment on Autism, CAHS.

barriers for a more socially inclusive Canada. It includes two recommendations to improve accessibility of the physical environment, support communication in public spaces (physical and online). The third brief, on the topic of postsecondary education, contains recommendations to expand inclusion and access, and to improve data collection regarding Autistic-specific registration and graduation rates.

Diagnosis, supports, and services

The first of three briefs in this theme was on the topic of mental health. It contains recommendations to work with the provinces-territories to eliminate barriers for qualified professionals to provide care across jurisdictions; provide opportunities for health professionals to better support Autistic people's experiences of mental health; ensure professionals have access to current research to optimize quality of care; and harness existing infrastructure to provide mental health information and resources to Autistic Canadians. The second brief was aimed at addressing disparities in resources and services across the lifespan and geographically. It contains recommendations to develop nationally-recognized standards of care; develop a federally-maintained database to assess metrics related to established standards of care; and promote equity in autism services funding and resource availability across the lifespan and across Canada geographically. The third brief was aimed at addressing disparities experienced by underserved sub-populations within the autism community, such as rural-and-remote, and BIPOC groups. It includes recommendations to establish policy initiatives to attract health care and paraprofessional providers to remote and rural areas; and to expand federal grant and partnership opportunities for autism-focussed community organizations serving immigrant, racialised, and ethnocultural individuals and their families.

Economic Inclusion

The first of three briefs in the Economic Inclusion theme was on the topic of employment. It contains recommendations to prioritize federal funding for person-directed case-management programs to support transition planning in high school; expand the accessibility and sustainable funding of successful federally-funded employer-demand-focussed initiatives such as Ready, Willing, and Able (RWA); and introduce transition-planning and career development in middle school. The second brief, on the topic of housing, contains recommendations to prioritize funding to increase awareness and support for providing autism-friendly housing; provide funding to establish a national autism housing platform; increase access to affordable housing by increasing supply; and promote accountability within the housing sector. The final brief, which was focussed on transportation and mobility, includes recommendations that disability-focussed upgrades to transit address the needs of neurodevelopmental disability; to ensure adequate funding for training and educational programs to enhance independence in transportation for Autistic adults; to Develop nationally recognized accessibility transport standards and regulations that consider the needs for Autistic individuals; and to establish a Transportation Autism and Developmental Disabilities Research Center.

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INTRODUCTION

In 2020-2021, the Public Health Agency of Canada (PHAC) requested the Canadian Academy of Health Sciences (CAHS) to conduct research and develop its now-published assessment report on autism.[2] Their work and report was aimed at summarizing the evidence on wide-ranging issues and topics relevant for developing a comprehensive National Autism Strategy (NAS), and was organized under three themes:
- Social inclusion
- Economic inclusion
- Diagnosis, supports, and services

In 2021, and in parallel with the CAHS work, the Autism Alliance of Canada (at that time named the Canadian Autism Spectrum Disorder Alliance, or Autism Alliance of Canada) developed a set of policy briefs to provide an early source of actionable policy recommendations for PHAC to address issues in these three areas. This resulting *Autism Alliance of Canada 2021 Policy Compendium*, presented here, was intended to supplement the thorough, but less recommendation-focussed, CAHS report. Similar to our prior *Autism Alliance of Canada 2020 Policy Compendium*, this policy compendium work was funded by Kids Brain Health Network (KBHN). Three multi-disciplinary working groups were struck, comprising researchers, professionals, students, Autistic advocates and other stakeholders from across Canada. Each group was led by one Autism Alliance of Canada-KBHN policy fellow. Working group members met monthly from June to November 2021, participating in a structured timetable of facilitated discussions, the goal of which was to develop three sets of focussed policy briefs. The aim of these briefs is to aid and support the federal government in taking actionable and effective steps in its early work to implement Canada's NAS.

APPROACH

Seven Autism Alliance of Canada-KBHN Policy Fellows each focused on a CAHS-designated theme, and conducted a scan of relevant information. A call for public stakeholders to participate in developing policy briefs on each theme resulted in the formation of five working groups. Stakeholders included Autistics, caregivers, policymakers, service providers from across Canada. Through participating in a structured timetable of facilitated discussions, each working group developed a set of policy briefs. Additional policy briefs and briefing notes written by Autism Alliance of Canada and members can be found at www.autismalliance.ca, or by contacting Autism Alliance of Canada at info@autismalliance.ca.

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[2] Canadian Academy of Health Sciences. (2022). Autism in Canada: Considerations for future public policy development - Weaving together evidence and lived experience. Ottawa (ON): The Oversight Panel on the Assessment on Autism, CAHS.

1. Section One: Social Inclusion

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Definition of the Term "Neurodivergent"

Neurodivergent refers to when someone's brain processes or learns differently from that which is considered "typical" or "neurotypical". This includes autistic people and those with other neurodevelopmental differences such as, but not limited to, Fetal Alcohol Spectrum Disorder, Attention Deficit Hyperactivity Disorder, and Specific Learning Disability.

SOCIAL INCLUSION BRIEF #1: A cohesive pan-Canadian framework to increase social inclusion

ISSUE

There are inconsistencies in the application of accessibility standards across federal and provincial organizations. Federal and provincial cooperation is essential for developing accessibility legislation that will help to improve social inclusion and reduce barriers for all people with disabilities[3,4]

BACKGROUND

- Social inclusion means being accepted and valued by society. It refers to having equal opportunities for all people, regardless of age, background, or ability, to access and benefit from resources and services, and participate fully in their community. Meaningful participation cannot be viewed as a privilege, but rather, as a necessity.

- It follows that Autistic and other Neurodivergent people living in Canada should be provided with the same level of social participation and engagement opportunities as everyone else.

- The federal government is taking positive steps to increase the social inclusion of people with disabilities in Canada[1,2], such as developing the Disability Inclusion Action Plan[5] that aims to increase quality employment, financial stability, access to federal programs and services, and an overall culture of inclusion in Canada.

- A more inclusive and accessible Canada benefits all Canadians.

CURRENT STATUS

- Existing accessibility standards apply to sectors within federal jurisdiction, such as banking, telecommunications, transportation industries and the Government of Canada itself. This means that private sectors and/or provincially and territorially funded buildings, transport, and sources of communication are not required to follow federally-regulated accessibility standards that facilitate social inclusion. Thus, the experience of social inclusion varies within and between provinces and territories in Canada.

- Although some provinces have developed provincial accessibility legislation (e.g., Ontario[6]), but other provinces and territories have not.

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[3] Accessible Canada Act, 2019
[4] Statistics Canada, Survey on Accessibility in Federal Sector Organizations, 2021. Retrieved 7 October from https://www150.statcan.gc.ca/n1/pub/11-627-m/11-627-m2021056-eng.htm
[5] Government of Canada, Employment and Social Development Canada (June 4, 2021). Retrieved October 17 from: https://www.canada.ca/en/employment-social-development/news/2021/06/canadians-invited-to-help-shape-canadas-first-disability-inclusion-action-plan.html
[6] Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008, S.O. 2008, c. 14

● A cohesive national structure for social inclusion is needed to ensure that all people living in Canada would have similar opportunities for social inclusion and community engagement.

KEY CONSIDERATIONS

This brief provides three recommendations that highlight options for the successful development, implementation, and monitoring of a cohesive national structure for social inclusion in Canada.

These recommendations draw on the tenets of Canada's ratification of the United Nations Convention on the Rights of Persons with Disabilities (2010), as well as the Accessible Canada Act (2019) and the Canadian Charter of Rights and Freedoms.

RECOMMENDATION #1: Extend federal accessibility legislation to private sector organizations across Canada.

● The Accessible Canada Act allows for the proactive identification, removal and prevention of barriers to accessibility wherever Canadians interact with areas under federal jurisdiction. Extending **accessibility legislation to cover all organizations that conduct business in Canada** would provide consistency across the country. The application could be similar to how the Personal Information Protection and Electronic Documents Act (PIPEDA) is applied so that provinces with their own substantively similar accessibility legislation would be generally exempt, but those without one would fall under the federal act.

RECOMMENDATION #2: Build federal-provincial-territorial partnerships to streamline accessibility standards.

● ***Convene a Federal-Provincial-Territorial First Ministers' conference*** in accessibility every 2 years to evaluate barriers experienced by disabled Canadians and to share knowledge about successful practices that different regions across the country have effectively implemented, improving social inclusion. Ensure that Autistic and other Neurodivergent voices and experiences are meaningfully represented. All Ministers involved in making decisions that influence the social participation of autistic and other Neurodivergent Canadians, such as the Minister of Employment, Workforce Development and Disability Inclusion, as well as Ministers of Health, Education, Children and Families, Social Services, Housing Ministries, are encouraged to be present at these meetings to facilitate cohesion across knowledge and practice across the country.

● At the First Minister's conferences, priority should be placed on ***establishing timelines and deadlines for private and public sectors to access funding*** that ensures equal opportunities for implementing effective practices for social inclusion across the country. Despite available opportunities for private and public agencies to apply for funding opportunities, cross government coordination is needed to ensure reasonable timelines and deadlines. An integrated calendar with relevant information about cross government funding opportunities would be helpful for ensuring agencies are given sufficient time to

complete applications. An example of an integrated calendar can be found on the federal government website related to funding opportunities for researchers, postdoctoral fellows, graduate students and research institutions[7].

RECOMMENDATION #3: **Identify shared social inclusion indicators and promptly report on the findings to monitor progress of social inclusion.**

- At the First Minister's conferences (see recommendation #2), priority should be placed on identifying social inclusion indicators that can be shared and used at the national and provincial-territorial levels in order to make relevant comparisons across the country (and eventually, internationally) and for capturing changes in the experience of social inclusion for autistic and other Neurodivergent Canadians. A study by the Department of Economic and Social Affairs of the United Nations was conducted on analyzing and measuring social inclusion in a global context[8]. This document highlights ideas for identifying concrete indicators of social inclusion in the United Nations, which may inform the process of identifying measures of social inclusion in Canada. For example, the authors recommend that social inclusion indicators need to be constructed using a participatory approach involving federal and non-federally funded agencies, Autistic and other Neurodivergent people themselves, and other relevant social partners.

- Once the government has collected the necessary data, results should be delivered in a prompt fashion as this is vital information that public and private agencies use to monitor progress and funding, programing and policy decision making. As of right now, the government has taken appropriate steps to collect data, but the dissemination of that data needs to be executed more quickly. For example, despite having conducted the Survey on Disability in Canada in 2017, the federal government of Canada is still referencing results from 2012, which impacts the ability for agencies across the country to make decisions that appropriately reflect the experiences of Canadians[9].

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[7] Integrated calendar of agency and interagency funding opportunities. Retrieved 18 October from
https://www.canada.ca/en/research-coordinating-committee/program-calendar.html
[8] Analysing and Measuring Social Inclusion in a Global Context Retrieved October 25 from
https://www.un.org/esa/socdev/publications/socialinclusion-globalcontext.pdf
[9] Canadian Survey on Disability, 2012 Retrieved October 25 from
https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2016001-eng.htm

SOCIAL INCLUSION BRIEF #2: Breaking down physical and communication barriers for a more socially inclusive Canada

ISSUE

Autistic and other Neurodivergent people living in Canada are confronted with significant physical, sensory and communication[10] barriers, such as limited access to built environments[11] and inaccessible language and signage. Universal accessibility to public spaces is currently lacking, but essential for all people living in Canada to engage and benefit fully from resources in their communities.

BACKGROUND

- The Accessible Canada Act[1] aims to make Canada barrier-free by January 1, 2040. This will be achieved by identifying, removing and preventing barriers in federal jurisdiction in priority areas, such as built environments and information and communication technologies, among others.

- As part of the accessible Canada initiative, a recent survey has revealed several key barriers related to accessibility, specifically within federal sector organizations[12] . For example, more than 62% of Canadians with disabilities, difficulties or long-term conditions have experienced at least one communication barrier, and nearly 45% have encountered barriers related to information and technology.

- Other consultations are considering issues related to disability inclusive spaces as part of Canada's first Disability Inclusion Action Plan[3].

CURRENT STATUS

- The federal government has taken positive steps to make Canadian society barrier-free for all individuals, particularly those with disabilities[1], however, there is more to be done[2].

- Consultations are important but need to reflect the needs of all people living in Canada with visible or invisible disabilities. The accessibility standards being developed often only reflect the needs of those with visible or physical disabilities. Autistic and other Neurodivergent people encounter barriers that are different from those experienced by individuals with other disabilities such as visual, auditory, or motor difficulties.

- Most critically, accessibility is not equivalent to, and does not necessarily foster a culture of inclusion, or lead to inclusion[3]. Access is one important aspect, but inclusivity must remain front and center to all consultations and policymaking.

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[10]In this context, communication relates to information used in physical and online spaces such as websites.
[11] Built environments refer to the availability, access, and use of buildings and public spaces, including libraries, post offices, schools, and parks, along with transport environments, such as inside planes and trains.
[12] Statistics Canada, Survey on Accessibility in Federal Sector Organizations, 2021. Retrieved 7 October from
https://www150.statcan.gc.ca/n1/pub/11-627-m/11-627-m2021056-eng.htm

KEY CONSIDERATIONS

As part of the initiatives of the Accessible Canada Act, federal departments, such as housing and transport, should work together to:

RECOMMENDATION #1: Improve Autistic and other Neurodivergent people's access and use of physical spaces, which can be facilitated by federal-provincial-territorial partnerships (see Brief #1, Recommendation #2).

- Ensure that federal buildings, transport, stations/airports and roads are designed, built and operated so that they are easy to use for all. This would include specific sensory and safety adaptations suited for people with a range of access needs. Examples of sensory adaptations can include, but are not limited to, visual supports, reduced lighting, dimmed noise, "quiet rooms" akin to breastfeeding rooms. Soundproofing rooms and measures to reduce light pollution for housing would also be helpful. In addition, safety adaptations can include wheelchair accessible playground equipment, wider door entrances, and open and unobstructed spaces.

- Build connections between building, housing and community developers, service agencies, and municipalities to integrate principles of inclusive design into new structures and developments[13]. Washroom facilities that are more flexible and inclusive of a wide range of users is an example of how inclusive building practices can make environments work better for a lot of Canadians. Parents with strollers, a female caregiver taking a man in a wheelchair on an outing, a gender questioning teenager who must choose which "side" is safer could all have their needs better met through inclusive design[14].

- Develop guidelines for architects, engineers, and other developers involved in the planning phase of building and/or incorporating modifications to existing infrastructure to support Autistic and other Neurodivergent people, and encourage planners to consult with Autistic and other Neurodivergent people in the process. Ontario's AllAccess program[15] is an example of a toolkit of resources that was developed to offer city builders a guide to understanding and implementing built environment designs that align with requirements outlined by the Design of Public Spaces Standard (DoPS) of the Accessibility for Ontarians with Disabilities Act.

- Promote integration of the principles of inclusive design into new developments and facilitate building connections between affordable housing developers, service agencies and Autistic people.

- Address the urgent need for a spectrum of support required for Autistic adults to live independently by promoting and funding a variety of support models, since there is no

[13] Policy Briefs to Guide the Development of a National Autism Strategy based on Community and Stakeholder Engaged Working Groups. Housing Brief 2: Addressing Housing Supply Challenges.
[14] Cholo, A (2019). *Best Practices for Inclusive Washrooms - a conversation*. National Outdoor Recreation Conference Rapid City, South Dakota. Slides Retrieved from https://www.recpro.org/assets/Conference_Proceedings/2019/Presentations/2019%20NORC%20A%20Cholo.pdf
[15] AllAccess: Creating Accessible Public Space with Human Space and the Canadian Urban Institute (2020). Retrieved from https://www.bdpquadrangle.com/ideas/blog/post/blog/2019/01/17/allaccess-creating-accessible-public-space-with-human-space-and-the-canadian-urban-institute

one size fits all approach to housing and support. Invest in funding models that allow for on-site support, as well as models that allow choice in both provider and home.

RECOMMENDATION #2: Improve the ease of use of language in public spaces both physical and online.

- Improve both physical and online information - ensuring that federal building and transport facilities provide information in physical and online formats that all people can easily access and understand, before and during a building visit or journey.

- Broaden the awareness and understanding of people with both visible and less visible difficulties through staff training across federal departments to understand the needs of people with physical, mental, cognitive or sensory impairments, so that they can provide better assistance.

- Federal funding opportunities can be created for agencies/organizations to hold awareness, acceptance, campaigns, and/or training around disability. Holland Bloorview Kids Rehabilitation campaign, Dear Everybody, provides an excellent example. This is a federally-funded campaign aimed to combat ableist language[16].

- Prioritize the development and implementation of standards for incorporating respectful strengths-based language related to Autistic and other Neurodivergent people into communications—for adoption by all federal departments, and by stakeholders[17].

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[16]It's time to end ableism. Start by talking about it. Retrieved on 22 October: https://deareverybody.hollandbloorview.ca
[17] Policy Briefs to Guide the Development of a National Autism Strategy based on Community and Stakeholder Engaged Working Groups. Information Brief 3: Communication Standards and Media Campaign to Improve Public Attitudes Towards Autism, Promoting Equity and Inclusion

SOCIAL INCLUSION BRIEF #3: Postsecondary education inclusion

Issue

Autistic and other Neurodivergent people living in Canada are confronted with significant barriers that can influence their success in postsecondary education. Trends indicate that more Autistic students are seeking out postsecondary education. Thus, it is paramount that the unique needs of Autistic students are adequately supported during their transition to, participation in, and graduation from postsecondary education.

Background

- There are is a growing number of Autistic students pursuing postsecondary education, with estimates suggesting almost half of transition-aged Autistic adults enroll in some form of postsecondary studies following high school[18].

- Although an estimated 50,000 Autistic youth become adults each year, 50% feel disconnected from employment or education opportunities in the first two years following high school[19].

- Autistic students report unique support needs in the areas of social interaction, communication, executive functioning, and academics[20] [21].

- Autistic students are also at-risk for a range of negative outcomes, including experiencing social isolation and other mental health issues, feeling under-supported, and ultimately drop-out[22] [23] (Cage & Howes, 2020; Jackson et al., 2018)

- There is a lack of evidence and literature which demonstrates the most effective instructional strategies to use for Autistic students[24] (Austin et al., 2017)

- Research shows Autistic students graduate postsecondary at a lower rate than Non-Autistic peers[16].

[18] Newman, L., Wagner, M., Knokey, A. M., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011). The Post-High School Outcomes of Young Adults with Disabilities up to 8 Years after High School: A Report from the National Longitudinal Transition Study-2 (NLTS2). NCSER 2011-3005. *National Center for Special Education Research*.

[19] Bizier, C., Fawcett, G., Gilbert, S., & Marshall, C. (2012). Developmental disabilities among Canadians aged 15 years and older. *Canadian Survey on Disability*.

[20] Jansen, D., Emmers, E., Petry, K., Mattys, L., Noens, I., & Baeyens, D. (2018). Functioning and participation of young adults with ASD in higher education according to the ICF framework. *Journal of Further and Higher Education*, *42*(2), 259-275.

[21] Jones, R. S., Huws, J. C., & Beck, G. (2013). 'I'm not the only person out there': Insider and outsider understandings of autism. *International Journal of Developmental Disabilities*, *59*(2), 134-144.

[22] Cage, E., & Howes, J. (2020). Dropping out and moving on: A qualitative study of autistic people's experiences of university. *Autism*, *24*(7), 1664-1675.

[23] Jackson, S. L., Hart, L., Brown, J. T., & Volkmar, F. R. (2018). Brief report: Self-reported academic, social, and mental health experiences of post-secondary students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *48*(3), 643-650.

[24] Austin, K. S., Peña, E. V., & Brennan, B. (2017). Promising Instructional Practices for College Students with Autism. *Currents in Teaching & Learning*, *9*(2).

Current Status

- In a recent environmental scan of the 258 publicly-funded Canadian postsecondary institutions (i.e., university, junior colleges/CÉGEP, technical/vocational), only 15 (6%) were identified to have at least one support for Autistic students[25].
  - Of the 15 institutions identified, 73% were located at universities, followed by 20% at technical and vocational colleges, and 7% at junior colleges/CÉGEP.

- Supports ranged from information provided within a section of the institution's website, followed by transition to university support, social group(s), peer mentoring, specialist tutoring and support with daily living, transition to employment support, and, finally, student-led societies and Autistic student advocates

- Universities and institutions in Central Canada (e.g., Ontario) had a higher number of provisions than expected

Key Considerations

- Currently there is no Canadian-specific research regarding the prevalence of Autism students transitioning from high school to postsecondary; without this data, it is challenging to adequately capture the extent to which supports are needed for Canadian Autistic students

- There is a lack of federal funding for provisions to be offered at postsecondary institutions

Recommendations

In collaboration with the Ministries of Education across provinces:

RECOMMENDATION #1: Expand access to and inclusion of postsecondary education among students with Autism.

- Prioritize the development and implementation of streamlined guidelines for postsecondary institutions regarding best practices on how to support the transition to, success in, and transition out of postsecondary services.

- Develop and evaluate transition to postsecondary and vocational programs. Alberta's Recovery Plan outlining strategies to promote access to inclusive postsecondary education may provide an outline (e.g.,https://www.alberta.ca/release.cfm?xID=805490BB50C95-C0FB-B434-0D8129475EA0C340)

- Federal and provincial funding opportunities for identifying best practices for promoting the success of Autistic and other Neurodivergent students in postsecondary education.

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[25] Ames, M. E., Coombs, C. E., Duerksen, K. N., Vincent, J., & McMorris, C. A. (2022). Canadian mapping of autism-specific supports for postsecondary students. *Research in Autism Spectrum Disorders*, *90*, 101899.

These best practices may include a variety of strategies including transition to postsecondary support, faculty and administrative training on how best to support and instruct Autistic students, mental health, peer mentorship, and learning strategies, and transition to vocation support.

- Streamline strategies on how to communicate with Autism and other Neurodivergent individuals in postsecondary level institutions. For example, Algonquin College provides a succinct resources for instructors on how to increase effectiveness in communication with Autistic people[26].

RECOMMENDATION #2: Improve data collection and tracking of the number of Autistic students graduating from high school, entering postsecondary institutions, and graduation and post-graduation employment rates.

- Unifying data collection on the number of Autistic students pursuing postsecondary education in order to advocate for resources and services.

- Collecting information on time to graduate and postgraduate entry into the workforce to track and evaluate effectiveness of identified strategies and interventions.

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[26] Algonquin College. Autism Spectrum Disorder. Retrieved from
https://www.algonquincollege.com/cal/files/2019/05/Autism-Spectrum-Disorder-For-Profs-Update.pdf

2. Section Two: Diagnosis, supports, and services

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DIAGNOSIS, SUPPORTS, AND SERVICES BRIEF #1: Mental health

ISSUE

Autistic Canadians do not have equitable access to mental health services.

BACKGROUND

- Mental health services are among the most unmet healthcare need for Autistic individuals across the lifespan[27,28,29].

- Canada ratified the United Nations Convention on the Rights of Persons with Disabilities over 10 years ago; however, Autistic Canadians are not provided with the same range, quality, and standard of free or affordable health care and programs as provided to other persons (Article 25).

- The federal government has committed to developing mental health standards with a focus on health equity[30]; Autistic Canadians and those with other neurodevelopmental disorders must be a priority area in work done to address the systemic inequities that remain present within our healthcare systems.

- Community mental health services are often not sufficiently equipped to assist Autistic people with mental health distress or mental health problems[31], which leaves people deprived of support from existing systems of care[32].

- There is a shortage of mental health professionals who are sufficiently trained in working with Autistic Canadians[33].

[27] Rast, J.E., Roux, A.M., Anderson, K.A., Croen, L.A., Kuo, A.A., Shea, L.L., & Shattuck, P.T. (2020). *National Autism Indicators Report: Health and Health Care*. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University.

[28] Tint, A., & Weiss, J. A. (2018). A qualitative study of the service experiences of women with autism spectrum disorder. *Autism : the international journal of research and practice*, *22*(8), 928–937. https://doi.org/10.1177/1362361317702561

[29] Autism Alliance of Canada (2020) "Policy Compendium: The Development of a National Autism Strategy through Community and Stakeholder Engagement" Retrieved from: https://www.Autism Alliance of Canada.ca/wp-content/uploads/2020/08/Autism Alliance of Canada-KBHN-Briefs-Compendium-_28102020-.docx.pdf

[30] Minister of Mental Health and Addictions and Associate Minister of Health Mandate Letter. Retrieved December 20 from: https://pm.gc.ca/en/mandate-letters/2021/12/16/minister-mental-health-and-addictions-and-associate-minister-health

[31] Autism Mental Health Literacy Project (AM-HeLP) Group. (2021). Mental Health Literacy Guide for Autism (1st digital Ed.). Retrieved from: https://www.yorku.ca/health/lab/ddmh/am-help/

[32] Lord, C., Charman, T., Havdahl, A., Carbone, P., Anagnostou, E., Boyd, B., ... & McCauley, J. B. (2021). The Lancet Commission on the future of care and clinical research in autism. *The Lancet.*

[33] Weiss, J. A., Lunsky, Y., & Morin, D. (2010). Psychology graduate student training in developmental disability: *A Canadian survey. Canadian Psychology/psychologie canadienne, 51*(3), 177.

CURRENT STATUS

- Long wait times, provider unfamiliarity with Autism, and location of services represent significant barriers of entry to critical mental health services[1,2].

- Regulatory requirements of mental health professionals (e.g., psychologists, social workers) are unique to each province/territory and professionals are largely restricted from practicing outside of their primary province. The Canadian Free Trade Agreement (CFTA) aims to promote labour mobility; however, there are continued significant financial and administrative barriers to cross-provincial/territorial service delivery for these highly skilled professionals. As a result, the limited number of professionals who are qualified to provide mental health services for Autistic Canadians are limited, in turn, in their reach.

- Some provinces have programs in place to address the shortage of qualified health professionals working with Autistic individuals. For example, the Extension of Community Healthcare Outcomes (ECHO) Ontario Autism program[34] is funded by the Ontario Ministry of Health and Long--Term Care and aims to build province-wide capacity and ability to screen, diagnose, and manage Autistic children and youth in Ontario. However, such programs are not standard across the country and only serve to increase the number of professionals within the province/territory in which they practice.

- Existing infrastructure, such as Wellness Together Canada, aims to improve access to mental health services for Canadians. These resources include targeted supports for individuals who may be at a higher likelihood of experiencing mental health distress (e.g., individuals affected by flooding, healthcare workers). However, no such resources exist for Autistic Canadians, nor are Autistic Canadians reflected in the existing resources, despite this group also having high likelihood of experiencing mental health distress[5].

KEY CONSIDERATIONS

- The shortage of mental health professionals is especially prevalent in northern, remote, and rural locations, where many Autistic individuals are unable to obtain care for their mental health needs.

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[34] ECHO Ontario Autism Website. Retrieved from: https://hollandbloorview.ca/services/programs-services/echo-autism

RECOMMENDATION #1: Work with provinces and territories to eliminate barriers for qualified professionals to provide care across jurisdictions

- We recommend working with national professional organizations (e.g., the Canadian Psychological Association) to review the licensing requirements of clinical professionals across provinces and territories. Allowing for easier cross-provincial/territorial practice may help eliminate barriers to accessing trained mental health professionals. Providing funds to facilitate such conversations between provinces and territories (e.g., through general meetings or working groups) is critical to making actionable progress towards this end.

RECOMMENDATION #2: Provide opportunities for the next generation of health professionals to better support Autistic people's experiences of mental health

- Provide funds to incentivize professional governing bodies to offer continuing education opportunities for currently practicing professionals. Such opportunities should be co-created alongside Autistic individuals.

- Building on the recommendation contained within Autism Alliance of Canada's 2020 Policy Compendium[3] to champion a comprehensive training program for professionals and expand upon the Autism Research Training Program through the proposed Centre of Excellence in Autism Research, training programs within this initiative should include a focus on providing mental health supports to Autistic individuals across the lifespan.

RECOMMENDATION #3: Ensure currently working professionals have access to up-to-date research that will improve their quality of care

- Providing better access to evidence-based journals and resources can also help to reduce barriers for mental health professionals seeking to develop their capacity to work with autistic individuals. Providing researchers with specified funds that encourage (and/or require) that federally-sponsored research be published in open-access journals may make research findings more accessible to working professionals.

RECOMMENDATION #4: Use existing infrastructure to provide mental health information and resources for Autistic Canadians

- Improve existing infrastructure (e.g., Wellness Together Canada) to be inclusive of mental health needs of Autistic Canadians. Resources such as the Autism Mental Health Literacy Project (AM-HeLP) Group's Mental Health Literacy Guide for Autism provide critical information for Autistic individuals and their families. Such pre-existing resources should be promoted at a national level to increase accessible information related to Autistic Canadians' mental health.

DIAGNOSIS, SUPPORTS, AND SERVICES BRIEF #2: Ages and settings

ISSUE

At the federal level, there is no oversight of care or resources provided to autistic individuals and their families and there are large disparities in resources across the lifespan and across the country.

BACKGROUND

Autism features a large range of symptoms, severity, and support needs but there is little guidance to navigate the provided service systems and evaluate suitability of available services[35]. Policy gaps often occur at critical times of transition and lead to decreased utilization of services, thus exacerbating vulnerabilities[36]. Further, the adequacy of policies intended to support autistic individuals and their families are vastly disparate across the country and leave certain regions especially vulnerable.

CURRENT STATUS

Provision of adequate, appropriate support and resources for autistic individuals is inequitable and often lacking across the lifespan as well as geographically within Canada.

KEY CONSIDERATIONS

Services are especially sparse for older individuals, those from minority populations, and those living in remote and rural communities. It is important to recognize and address the compounding challenges that underserved communities experience in accessing diagnostic and supportive services.

RECOMMENDATION #1: Develop nationally-recognized standards of care for services provided to autistic individuals.

- Services should be evidence-informed, accessible, person-centered, address the expressed needs of each individual, and be provided in a timely manner. In addition to individually-directed services (e.g., occupational therapy, mental health) standards

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[35] Lord, C., Brugha, T.S., Charman, T., Cusack, J., Dumas, G., Frazier, T., Jones, E.J.H., Jones, R.J., Pickles, A., State, M.W., Taylor, J.L., Veenstra-VanderWeele, J. (2020). Autism spectrum disorder. *Nature Reviews Disease Primers, 6*(5).

[36] Kennedy-Hendricks, A., Epstein, A.J., Mandell, D.S., Candon, M.K., Marcus, S.C., Xie, M., & Barry, C.L. (2018). Effects of state autism mandate age caps on health service use and spending among adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry, 57*(2), 125-131.

for service provision should also include resources for families and caregivers such as respite care.

● Implementation of nationally-recognized standards of care increases the portability of diagnoses and continuity of care across provinces and territories.

● The UK's National Institute for Health and Care Excellence has established and regularly updated clinical guidelines for support and management of ASD in both youth and adults[37,38]. These guidelines include general standards of care, information about evidence-based practices for different features of ASD, a broad lens on what these features or coexisting symptoms may be, and guidance around interventions to avoid. The Cooperative Research Centre for Living with Autism (Autism CRC) is currently undertaking a similar initiative to support autistic individuals, families, and practitioners in decision-making around service provision[39].

RECOMMENDATION #2: **Develop a federally-maintained and -mandated database to assess metrics related to established standards of care.**

● Development of a national database can facilitate deeper understanding of the current state of service provision, identify where need lies within the current system, define targets, and measure success in reaching such goals. In turn, this approach can inform future research and revisions to standards of care in order to continue moving Canada's autism service model forward.
  ● Similar initiatives include the use of the PHAC-supported Canadian Chronic Disease Surveillance System or the Canadian Cancer Registry from Statistics Canada to monitor prevalence rates and service usage in conditions such as dementia, osteoporosis, and cancer in order to inform planning and allocation of resources[40,41].

● The database should include service metrics such as services available, time to diagnosis or service access, age of diagnosis, funding, outcomes of services (short- and long-term), as well as demographic information of the populations accessing such services, such as language spoken, and the number of autistic individuals by province.

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[37] United Kingdom National Institute for Health and Care Excellence. (2021). *Autism spectrum disorder in adults: diagnosis and management (clinical guideline 142).*

[38] United Kingdom National Institute for Health and Care Excellence. (2021). *Autism spectrum disorder in under 19s: support and management (clinical guideline 170).*

[39] Autism CRC. (2021). *Update on new practice guideline for supporting the development and participation of children on the autism spectrum and their families.*

[40] Canadian Cancer Statistics Advisory Committee. (2019). Canadian Cancer Statistics 2019. Toronto, ON: Canadian Cancer Society.

[41] Public Health Agency of Canada. (2019). Canadian Chronic Disease Surveillance System (CCDSS), Data Tool 2000–2017, 2019 Edition. Ottawa (ON): Public Health Agency of Canada.

- The information held in this database should be made known and accessible to the public, similar to Alberta's 211 helpline or AIDE Canada's resource compilation[42,43]. Creation of informational resources and provision of system navigation can assist in understanding and utilization of available resources.

RECOMMENDATION #3: Create equity of funding and resource availability across the lifespan and country such that all Canadians have access to their necessary support services.

- Services should be provided to all following a needs-based model rather than based on diagnosis or age. This approach creates fairness in access to resources across the lifespan as well as across diagnoses and for those waiting for assessment.

- Funding should be made equitable across the country through avenues such as expanding the Canada Health Act or via dedicated federal transfers in exchange for provincial commitments to meeting established standards of care.

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[42] 211. (2020). 211 Alberta. https://ab.211.ca/
[43] AIDE Canada. (2020). The Autism and/or Intellectual Disability Knowledge Exchange Network. Public Health Agency of Canada.

DIAGNOSIS, SUPPORTS, AND SERVICES BRIEF #3:
Underserved populations

ISSUE

In Canada, there are significant disparities in access to evidence-informed interventions (EIS) for autistic individuals and their families from underserved populations. Those living in remote and rural areas have limited access to EIS compared to cities and urban areas. Additionally, BIPOC communities are also more likely to experience barriers such as racism and stigma impeding their access to EIS. It is crucial that the needs and priorities of underserved communities are considered and integrated into the development and implementation of EIS.

BACKGROUND

- Underserved populations are defined as a group of people whose circumstances create challenges to seeking or obtaining health and other essential services. Underserved populations include BIPOC, residents of rural and remote communities, residents of reserves, single-parent households, migrant and immigrant communities, and those with low income[44].

- Since autistic individuals from underserved communities tend to receive a diagnosis for their child later in life, their access to early intervention and other EIS is often delayed and limited[45,46].

- Barriers to accessing EIS for underserved communities include discrimination, language, low income, transportation limitations, precarious employment, and cultural factors such as poor understanding of therapy potential, family traditions, and specific health beliefs[47,48].

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[44] Malik-Soni N, Shaker A, Luck H, et al. Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. *Pediatr Res*. Published online 2021. doi:10.1038/s41390-021-01465-y

[45] Daniels AM, Mandell DS. Explaining differences in age at autism spectrum disorder diagnosis: a critical review. *Autism*. 2014;18(5):583-597. doi:10.1177/1362361313480277

[46] Constantino JN, Abbacchi AM, Saulnier C, et al. Timing of the Diagnosis of Autism in African American Children. *Pediatrics*. 2020;146(3). doi:10.1542/peds.2019-3629

[47] Fong V, Lee BS, Iarocci G. A community-engaged approach to examining barriers and facilitators to accessing autism services in Korean immigrant families. *Autism*. Published online July 2021:13623613211034068. doi:10.1177/13623613211034067

[48] Ravindran N, Myers BJ. Cultural Influences on Perceptions of Health, Illness, and Disability: A Review and Focus on Autism. *J Child Fam Stud*. 2012;21(2):311-319. doi:10.1007/s10826-011-9477-9

CURRENT STATUS

Across Canada, there are disparities in access to EIS for autistic individuals and their families from underserved communities[49,50].

KEY CONSIDERATIONS

Autistic individuals and their families from underserved communities experience significant challenges accessing EIS due to geographic, language and communication, transportation, and financial barriers. Additionally, members from racialized and ethno-cultural groups report the lack of culturally sensitive services available for their communities. Addressing these challenges and providing autistic individuals and their families with the most effective and culturally appropriate services requires adaptation to EIS or the development of new EIS in partnership with the community.

RECOMMENDATION #1: Establish rural/remote educational policy initiatives to attract health care and paraprofessional providers to remote and rural areas.

- Create education initiatives that focus on recruiting students from remote and rural areas by offering scholarships, bursaries, and forgiving student loans in exchange for providing services in these areas. One example of this is the Rural Education Action plan which has partnered with the UBC Faculty of Medicine, The Ministry of Health Services of BC and the BC Medical Association to address the need for physicians in rural practice[51].

- Create partnerships with Indigenous communities to offer educational training opportunities for members to gain qualifications to deliver services in their own communities. Additionally, incorporating cultural sensitivity training into post-secondary education and training will help improve the cultural competency of service providers and professionals.

- While providing remote consultations has increased more recently and may help address geographic barriers, it is essential to address the limited access to fast, high-speed internet and technology equipment in remote and rural areas. Regulations should be made regarding acceptable target speeds for broadband connectivity in these areas.

[49] Hoogsteen L, Woodgate RL. Centering autism within the family: a qualitative approach to autism and the family. *J Pediatr Nurs*. 2013;28(2):135-140. doi:10.1016/j.pedn.2012.06.002

[50] Young A, Nicholas DB, Chamberlain S-P, Suapa N, Gale N, Bailey AJ. Exploring and building autism service capacity in rural and remote regions: Participatory action research in rural Alberta and British Columbia, Canada. *Autism*. 2018;23(5):1143-1151. doi:10.1177/1362361318801340

[51] UBC. (2021). *Rural Education Action Plan*. https://health.ubc.ca/reach/initiatives/rural-education-action-plan

RECOMMENDATION #2: **Create federal grants and partnerships to support cultural community organizations that serve immigrant, racialized, and ethno-cultural individuals and their families.**

- Prioritize federal funding grants for cultural community organizations to provide targeted supports for ESL individuals and their families. These organizations could provide access to service navigators, translators, interpreters that are provided to families without cost, and informational resources accessible to families in their own language[52,53].

- Capacity building initiatives should be created that involve cultural outreach activities and co-creating culturally appropriate services and supports with Indigenous leaders and cultural organizations. Collaborating with stakeholders from diverse backgrounds and engaging directly with these individuals will provide a better understanding of the barriers they experience, and their needs and priorities when it comes to EIS.

- Provide federal research grants that are community-based and that focus on intersectional, inclusive, and strengths-based practices. This will advance our knowledge base and provide evidence-based solutions that are contextually grounded and relevant to the lives of our increasingly diverse population in Canada.

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[52] *SAAAC Autism Centre*. (2021). https://saaac.org
[53] *Here and Now Community Society*. (2019). https://www.hereandnowca.org

3. Section Three: Economic Inclusion

ECONOMIC INCLUSION BRIEF #1: Employment

ISSUE

Canada is committed to ensuring labor market accessibility to all individuals with a disability. However, The employment outcomes of Autistic individuals remain poorer than that of the neurotypical population and also peers with other disabilities. Potential exists to leverage existing programs to improve the inclusion of Autistic individuals in the labor market.

BACKGROUND

In Canada, Working age Autistic individuals have the lowest employment rate at 14.3% compared to the general population (92.7%) and other disability groups (45.2%)[54]. Moreover, the majority of those who managed jobs are underemployed[55].

Pre-employment programs are a critical component of the employment support ecosystem. The programs provide Autistic individuals across the lifespan with the necessary skills to improve employment readiness, particularly those who transition to work from secondary and post-secondary education.

Workplace inclusion programs, another component of the employment ecosystem, assist job seekers with disabilities to find a job and who need regular, ongoing support in the workplace to keep a job.

The significant under-engagement in the labor force demonstrates the need to consider new approaches to improve the outcomes of the employment support programs.

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[54] Sinneave. 2021. Ecosystem approach to employment ant Autism.
https://sinneavefoundation.org/news/ecosystem-approach-employment-autism/ .Retrieaved 19 December 2021
[55] Baldwin, S., Costley, D., & Warren, A. (2014). Employment activities and experiences of adults with high-functioning autism and Asperger's disorder. *Journal of autism and developmental disorders*, *44*(10), 2440-2449

CURRENT STATUS

The federal government provided support to many Autism-specific pre-employment programs that offer transition support for high school students, age 15 and above (e.g.,ProjectSEARCH, Worktopia, CommuniyWorks Canada). The support duration ranges from 12 weeks to one year.[56]

Ready, Willing and Able (RWA) is a partnership project funded by the Government of Canada, designed to increase the workforce participation of people with intellectual disabilities (ID) and Autism. While it has multiple elements, it primarily focuses on employer engagement, or the 'demand side' of employment, rather than the traditional approach of focusing mainly on the 'supply side', e.g., job readiness training. The project operates across 20 sites in each of the 13 Provinces and Territories[57].

KEY CONSIDERATION

RECOMMENDATION #1: Prioritize federal funding for person-directed case-management programs focused on education/employment starting in high school and bridging the transition to the workforce

Prioritizing federal funding grants for Autism-focused case management pre-employment programs which cross independent living, education, and employment domains. A cross-domain case management model provides information, resources, and guidance in all three domains to help overcome cross-system barriers when possible. Any barrier experienced in one domain makes it more challenging to progress in other domains. In addition, the prioritized programs should provide long-term follow-up support to ensure the individual is proceeding toward their employment goals[58].

Re-activating funds under Youth Employment and Skills Strategy, a horizontal cross-domain initiative involving eleven federal departments and agencies, and increasing funding duration beyond the three-year limit. This allows case management support to bridge from high school to labor[59].

[56] Autism Alliance of Canada. (2020). Policy Compendium: The Development of a National Autism Strategy through Community and Stakeholder Engagement

[57] Stainton, T et al. (2018). Read, Willing and Able initiative evaluation report. BC university. https://cic.arts.ubc.ca/files/2019/05/Ready-Willing-and-Able-Evaluation-Final-Report-January-2018-1.pdf. Retried 10 November 2021

[58] McCormick, S. T., Kurth, N. K., Chambless, C. E., Ipsen, C., & Hall, J. P. (2021). Case Management Strategies to Promote Employment for Transition-Age Youth With Disabilities. *Career Development and Transition for Exceptional Individuals*, *44*(2), 120-131

[59] Government of Canada. (2020). Apply for funding under the Youth Employment and Skills Strategy Program: National or Regional. Retrieved 20 November 2021. https://www.canada.ca/en/employment-social-development/services/funding/youth-employment-skills-strategy-program.html

RECOMMENDATION #2: Expand the accessibility and sustainable funding of successful federally-funded employer-demand-focussed initiatives such as Ready, Willing, and Able (RWA)

Review service eligibility criteria to ensure persons Autistic individuals who do not have intellectual disability ID (IQ of 70) can access necessary disability supports.

Developing bilateral agreements between the Federal and Provincial/Territorial Governments for sustained funding for RWA in exchange for commitments on ensuring an effective policy and support regime for employment of people with ID and ASD

Support the expansion of RWA over more geographical locations (RWA currently operates in 20 sites) to enhance equality of access regardless of where the individual resides.

RECOMMENDATION #3: Introduce transition and career development into middle school.

Promoting programs for life skills training for middle school Autistic students (age 12 to 15) targeting improving employment readiness and overcoming social and decision-making challenges. The current federally funded Autism-specific transition programs only target high school students. Research suggested that elementary and middle schools should explore basic knowledge and values related to the transition to employment[60][61]. Expanding the current Autism-specific programs such as Worktopia, ProjectSEARCH, School Work Canada, and Employment Works to cover middle school students should be explored.

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[60] Elias, M. J., & Friedlander, B. S. (1994). The Social Decision Making and Life Skills Development Program: A Framework for Promoting Students' Social Competence and Life Skills and Preventing Violence, Substance Abuse and Related Problem Behaviors
[61] Lindemeier, Y. (2012). The Educational Transition Resource Guide for Parents of Middle School Students with Disabilities

ECONOMIC INCLUSION BRIEF #2: Housing

ISSUE

Canada's federal, provincial and municipal governments have declared adequate housing as essential to one's sense of dignity, safety, and inclusion. However, the current multifaceted and multi-jurisdictional housing system is complex and does not allow equitable access to housing. Autistic people living in Canada have the right to housing that is safe, affordable, accessible and sustainable, which is not currently being met.

BACKGROUND

Research has identified a "double cliff" in the lifespan of Autistic adults where significant housing vulnerabilities arise. The first cliff is at the transition to adulthood (age 18–30) due to lack of access to affordable housing. The second cliff is at the transition from mid-life into later years (age 50–55) when there is a need to sustain housing when the original primary caregivers are no longer able to provide support and where a broader circle of support is lacking.

Autistic individuals and their families have housing needs that vary significantly according to their disability profiles, lifespan, and socio-economic condition.

Housing typologies for Autism vary from supportive housing with full-time care, to semi-independent living, to affordable or market housing[62].

Shortage of Autism-friendly housing options resulted in a long waitlist for the limited existing housing stock, affecting the ability to get a stable job and attend school. Research indicated that lack of community-based support, including housing, resulted in significant psychological and mental health implications[63].

CURRENT STATUS

The National Housing Strategy prioritized federal investment for housing of people with disabilities[64], including those with Autism and related disorders. Three programs under the National Housing Strategy have responded to the lack of suitable and affordable housing by increasing the supply of rental units. Despite this effort, the supply fell short of the goal set by the NHS, and was concluded to be insufficient in meeting the housing needs of Autistics in Canada. Additionally, the suitable housing stock remains insufficient given the current waitlist,

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[62] Nagib, W., & Williams, A. (2017). Toward an autism-friendly home environment. Housing Studies, 32(2), 140-167.

[63] Autism Alliance of Canada. (2020). Policy Compendium: The Development of a National Autism Strategy through Community and Stakeholder Engagement

[64] CMHC-SCHU. 2019. Government of Canada Invests in Affordable Housing for People with Disabilities in Hamilton. https://www.cmhc-schl.gc.ca/en/media-newsroom/news-releases/2019/government-canada-invests-affordable-housing-people-disabilities-hamilton. Retrieved 12 December 2021.

and the housing community lacks awareness about the specific needs of Autistics and their families. This stresses the dire need of a comprehensive strategy to address the housing crisis.

However,

KEY RECOMMENDATIONS

Cross-government initiatives under the federal government's leadership are required to promote awareness of housing needs for Autism and to assist Autistics and their families in finding appropriate housing options.

RECOMMENDATION #1: Prioritize funding to increase awareness and practice on providing autism-friendly housing.

Support housing partners to pilot an autism housing project to inform housing practice and awareness of Autism to ensure the housing needs of autistic people are well understood across the housing sector.

Support the establishment of academic courses/programs in architecture and social science and programs that offer specialization in a disability-friendly built environment. Research evidence suggests that the absence of such courses is responsible for practitioners' lack of interest and knowledge in developing designs for people with disabilities in general and with Autism in particular. Please refer to the Housing through an Autism Lens policy brief for details or click here for the webpage.

RECOMMENDATION #2: Provide funding to establish a national autism housing platform.

Establishing an online forum and resource hub for sharing housing options and resources for autistic adults and others with intellectual or developmental disabilities. A good example is the Housing Autism Network of USA[65]. The Platform includes a real-estate-housing directory where Autistics and their families can explore the available autism-friendly housing options across the county. The Platform also provides a hub for many housing organizations to collaborate and learn on ways to address the barriers for new, sustainable quality housing for people with a learning disability and/or Autism.

RECOMMENDATION #3: Increase access to affordable housing by increasing supply.

Avenues that can be leveraged to increase supply are:

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[65] Autism Housing Network. https://www.autismhousingnetwork.org/

- Increase collaboration between all levels of government (federal, provincial and municipal) to accelerate and add certainty to the process of adding new supply.
- Collaborate with all levels of government on a clear plan to increase affordable housing for renters and owners at all income levels using taxation, spending and regulatory levers.
- Increase flexibility of funding models so federal investments can be better leveraged by non-government partners in regions where there is low provincial or municipal government investment in affordable housing.

RECOMMENDATION #4: **Promote accountability within the housing sector.**

Promote accountability by improving measurement and reporting mechanisms so that regular, progress reports on the status of affordable housing are publically available, as well as ensure data collection and reporting includes metrics for accessibility and inclusion.

ECONOMIC INCLUSION BRIEF #3: Transportation & Mobility

ISSUE

Canada is committed to providing inclusive and reliable transportation for people with disabilities. However, for most Autistic individuals, this goal has yet to be fully realized, leaving them to rely on family and friends to meet their transportation needs. This, in turn, affects their engagement in employment, education, healthcare, and social pursuits. Federal, provincial, and local cooperation is needed to improve transportation accessibility and reliability for Autistic individuals.

BACKGROUND

- Many Autistic individuals encounter challenges in obtaining a driver's license compared to neurotypical peers. Even those who obtained a license rarely drive due to driving confidence and driving performance challenges. They also find difficulties navigating the public transit system with the associated anxiety-inducing noisy and busy environments[66, 67]
- Walking either to transit or to activities is also a challenge for many Autistics, as they have difficulty crossing roads, judging distance, and comprehending direction. Even when they can walk, the propensity to walk is low among this population since the activities they typically visit are not within walking distance[68,69]
- Because of their difficulties with driving, taking transit, and walking, most Autistics are highly reliant on socially-provided transportation service from family and friends[70, 71]
- Accessibility challenges to reliable transportation options for autistic individuals limit their engagement in employment, education, healthcare, social opportunities and contribute to a deteriorating quality of life[72, 73]
- Transport policies and programs designed for persons with these challenges in mind are needed

[66] Lindsay, S. (2017). Systematic review of factors affecting driving and motor vehicle transportation among people with autism spectrum disorder. Disability and rehabilitation, 39(9), 837-846

[67] Daly, B. P., Nicholls, E. G., Patrick, K. E., Brinckman, D. D., & Schultheis, M. T. (2014). Driving behaviors in adults with autism spectrum disorders. *Journal of autism and developmental disorders*, *44*(12), 3119-3128

[68] Feeley, C. (2010, January). Evaluating the transportation needs and accessibility issues for adults on the autism spectrum in New Jersey. In 89th annual meeting of the transportation research board, Washington, DC.

[69] Feeley, C., Deka, D., Lubin, A., & McGackin, M. (2015). Detour to the right place: A study with recommendations for addressing the transportation needs and barriers of adults on the Autism Spectrum in New Jersey. Rutgers University

[70] Dudley, C., Emery, H., & Nicholas, D. (2012). Mind the gap: the missing discussion around transportation for adolescents and adults with autism spectrum disorder. *Policies across the Provinces from a Lifespan Perspective: Transportation Report*

[71] Dudley, C., Emery, H., & Nicholas, D. (2012). Mind the gap: the missing discussion around transportation for adolescents and adults with autism spectrum disorder. *Policies across the Provinces from a Lifespan Perspective: Transportation Report*

[72] Lindsay, S. (2017). Systematic review of factors affecting driving and motor vehicle transportation among people with autism spectrum disorder. Disability and rehabilitation, 39(9), 837-846

[73] Feeley, C. (2010, January). Evaluating the transportation needs and accessibility issues for adults on the autism spectrum in New Jersey. In 89th annual meeting of the transportation research board, Washington, DC.

CURRENT CONTEXT

- The federal government has taken positive steps to make transportation within the federal jurisdiction barrier-free for all individuals, particularly those with disabilities. The Accessible Transportation for Persons with Disabilities Regulations (ATPDR) was recently created, and most provisions came into force on June 25, 2020. Most provinces and a few municipalities have also issued transportation accessibility documents. In addition, intercity bus operators have issued the Intercity Bus Code of Practice, a voluntary commitment to serve people with disabilities[74]. However, an environmental scan of transportation policy documents revealed that little existed to address the specific needs of Autistic individuals[75].
- Funding programs for Autistics rarely mention the need for safe, efficient, and reliable transportation. One promising example from Ontario (The Passport Program) has funding for adults with a developmental disability to develop skills in utilizing transportation services[76].

KEY CONSIDERATIONS

Cross-government coordination under the federal government's leadership is required to address the compounding Autism-specific transportation challenges.

RECOMMENDATION #1: **Transit upgrades for disability should address the needs of neurodevelopmental disability**. Currently, upgrades are designed to meet the needs of seniors and persons with physical or sensory disabilities (vision/hearing impairment). Incorporation of new research and innovative best practices in these areas is needed.The International Transport Forum (2009) for cognitive and mental health transport identifies good practice ideas across European countries like: the presence of staff at interchanges, real-time audio on all transit including buses, physical design features that include pictures, and thoughtful layout of facilities. Also, there is promising research on information technology (IT) for individuals with cognitive disability and brain injury that may enhance independence for Autistics who are capable of managing IT systems.

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[74] Government of Canada. (2020). Accessible transportation. https://tc.canada.ca/en/corporate-services/policies/accessible-transportation. Retrieved 20 November
[75] Dudley, C., Emery, H., & Nicholas, D. (2012). Mind the gap: the missing discussion around transportation for adolescents and adults with autism spectrum disorder. *Policies across the Provinces from a Lifespan Perspective: Transportation Report*
[76] Dudley, C., Emery, H., & Nicholas, D. (2012). Mind the gap: the missing discussion around transportation for adolescents and adults with autism spectrum disorder. *Policies across the Provinces from a Lifespan Perspective: Transportation Report*

RECOMMENDATION #2: Ensure adequate funding for training and educational programs to enhance independence in transportation for Autistic adults.

Funding initiatives are needed for: supporting transportation educational training programs for Autistics to develop skills in utilizing various transportation modes (like those of the Ontario Passport program)[6], developing individualized education programs with deriving goals, educating families and the communities on transportation and mobility options for Autistic, ensure adequate training for transit operators on accommodating the needs of Autistic individuals.

RECOMMENDATION #3: Develop nationally recognized accessibility regulations that consider the needs for Autistic individuals

Transport standards should require compulsory training and education for all public transport staff on delivering inclusive services for less visible disabilities such as autism.

Transportation providers must develop an accessibility action plan focusing on meeting the needs of people with invisible disabilities.

Establish protocols that support Autistics and their families to collaborate more in the decision-making process for municipal transit initiatives to represent their needs.

Addressing the current gaps in accessibility regulations related to wayfinding and navigation systems, as identified by a recent environment scan[77], which is a mobility concern for Autistic individuals.

RECOMMENDATION #4: Establish a Transportation Autism and Developmental Disabilities Research Center

Establishing a national research center allows for a dedicated interdisciplinary team of experts to explore and address these critical transportation and mobility barriers that limit the successful community integration of this vulnerable population. The work undertaken at the center would encompass the review, analysis, and development of "best practice" recommendations of transportation-focused strategies for rural, suburban and urban locations.

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[77] Lau, S-T., Nirmalanathan, K., Khan, M., Gauthier, C., Maisel, J., Novak, A. (2020). A Canadian Roadmap for Accessibility Standards, Canadian Standards Association, Toronto, ON