

**Policy Compendium:
The Development of a National Autism Strategy through
Community and Stakeholder Engagement**

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EXECUTIVE SUMMARY

On April 1, 2019, CASDA unveiled the Blueprint for a National Autism Strategy (NAS), as a framework outlining 5 key areas of focus: Research and Governance, Affordability and Access, Employment, Housing, and Information. In March 2020, with funding from Kids Brain Health Network (KBHN), CASDA struck Policy Development Working Groups to research information and synthesize policy options to inform the development of a NAS. The multi-disciplinary working groups comprised researchers, professionals, students, Autistic Canadians and stakeholders from across the country. Members of each group met over the course of 5 months from April to September 2020. These meetings resulted in a rich discourse, which served as the basis for concise and focused policy briefs. The aim of these briefs is to aid and support the federal government in taking actionable and effective steps towards the development of a NAS focused on the 5 priority areas.

RESEARCH AND GOVERNANCE

Many programs that support Autistic Canadians are funded and delivered at the provincial and territorial levels. Because of this, there is a lack of information sharing between the Federal government and its partners. This leads to an inconsistent application of research and a variety of service types available within those regions and, ultimately, fragmented knowledge sharing across the country. As it currently stands, there is no set of national standards on research programs and evaluation to provide consistent support for Autistic Canadians and their families across a lifespan. Recommendations in this area include the following:

1. **A Leadership Framework:** create a cross-government leadership coordinating commission and establish an FPT implementation framework.
2. **Federal Leadership and Provincial/Territorial Engagement:** establish a federal-provincial-territorial First Ministers' Meeting and the brief includes 10 specific actions for a First Ministers' Meeting.
3. **Recommendations on Advisory for a NAS:** create an advisory group for a NAS that models the structure of Accessibility Standards Canada; ensure that standards development review processes are both open and inclusive; and, finally, ensure an equity, diversity, inclusion lens to include Autistic people and service providers who are women, Indigenous, from rural and remote communities, racialized immigrants and newcomers, and from the LGBTQ+ community as members of the board of the proposed advisory panel or organization.

AFFORDABILITY & ACCESS

In Canada, challenges with affordability and access experienced by autistic individuals and their families can create a barrier to the services and support they need to reach their full potential and live a fulfilling life. The following briefs focus on three specific challenges associated with affordability and access in Canada:

1. **Federal Disability Tax Measures:** continue progress towards implementing the recommendations outlined in the 2019 First Annual Report from the Disability Advisory Committee; reform and modify disability tax measures; and raise awareness for tax measures among Autistic Canadians.
2. **Early Win Opportunity - Reforming the Disability Tax Credit:** replace Form T2201 with new application form(s) that better reflect the challenges faced by children and adults with neurodevelopmental conditions; expand the number of practitioners eligible to fill out the renewed DTC application form; recognize autism as a lifelong neurodevelopmental condition; and make DTC refundable to ensure it meets the needs of low-income Autistic Canadians.
3. **Improving Access in Society:** champion a comprehensive training program for professionals to expand capacity; prioritize mental health initiatives within existing federal funding initiatives; and introduce a national autism waitlist reduction initiative.
4. **Federal Leadership:** Recommendations in this brief consist of actions for the First Ministers' Meeting recommended in the Research and Governance area, and include: enhance autism diagnosis portability across Canada; implement early developmental interventions services; examine service delivery models; access P/T disability income assistance programs and implement reforms as needed; expand the capacity of P/TI education systems to adequately educate and provide support to Autistic children; and improve P/TI waitlist data collection and reporting.
5. **Early Developmental Intervention Services for Children on the Autism Spectrum:** adopt the Enhanced 18-Month Well-Baby Visit to grant children access to early developmental intervention services; invest in sustainable linkages of population-level databases to determine the trends in prevalence and developmental health of Autistic children over time; and coordinate a taskforce to develop a standard set of universal early developmental intervention and ensure delivery across the country.

EMPLOYMENT

Only 3 in 10 Autistic Canadians report being employed. Additionally those who are employed are often what we call 'underemployed', meaning that they are unwillingly working shorter hours for less pay and often at jobs that are below their intellectual potential. The following briefs address pre-employment programs and inclusive workplaces in Canada:

1. **Pre-Employment Programs:** expand and enhance current pre-employment programs; encourage provinces/territories to implement programs within high-schools and post-secondary institutions to improve opportunities of finding employment and preparing individuals for employment; establish sustainable autism-specific funding platforms, ensure continuous evaluation of these funded programs to ensure effectiveness and merit for sustainability efforts.

2. **Inclusive Workplaces:** increase and develop employer training initiatives and opportunities for hiring and supporting Autistic employees; commit to a workplace adjustment/accommodation fund to support employers who hire Autistic individuals; select, disseminate, and help implement best practices from federally funded programs that demonstrate effective recruiting, selecting, hiring, onboarding, and retention models used by Canadian employers; shifting from ‘one-size-fits-all’ model to competency-based hiring; increase access to and implementation of on-the-job supports for Autistic employees; allow for and provide alternative methods of funding to support individuals on the autism spectrum in the workplace.

HOUSING

Limited housing options exist for people with developmental disabilities generally and is compounded by a lack of autism-specific support. In addition, many Autistic adults do not have sufficient income through employment or social assistance to live independently.

Recommendations in this area include the following:

1. **Income Support Needs Related to Housing:** convene Federal/Provincial/Territorial working group to design a disability supplement to the Canada Housing Benefit; work with provinces and municipalities on affordable, stable rent control; and implement the recommendations from the Solutions Lab “Designing a Registered Disability Savings Plan Homeownership Plan”, allowing RDSP beneficiaries to withdraw funds to be used towards a downpayment for a home.
2. **Addressing Housing Supply Challenges:** direct Canada Mortgage and Housing Corporation to expand the current indicators used for inclusive housing to include persons with developmental disabilities allowing for full inclusion; build connections between affordable housing developers and service agencies, to integrate principles of inclusive design into new developments; appoint Autistic representation to the National Housing Council.
3. **Early Win Opportunity for the NAS:** leverage existing NHS innovation and research investments and include specific opportunities to better target existing initiatives to respond to the needs of Autistic Canadians.

INFORMATION

Information includes evidence-based information products, such as clinical or professional practice, guidelines, professional training, programs, education for families, or public media campaigns, as well as data systems used in service navigation by caregivers and policymakers, and can be found in government administrative databases, clinical community organization, and large research cohort databases. The following briefs aim to improve information for each of the above areas:

1. **Integrating Data Systems:** incentivize the study of administrative databases for each service system (Education, Social, Health) across PTs to identify strong models for PTs to follow in



terms of minimal data elements, cross-linking to other databases, and other standards required for a Learning Health System; and set PHAC-recommended minimum data elements (data standards) for PT service systems, to support the needs of ongoing or projected federal data collection initiatives such as the PHAC National Autism Spectrum Disorder Surveillance System.

2. **Coordinated Provincial Autism Program Information Sharing:** fund a gap analysis to determine information needs of PT policymakers to make decisions relevant to autism policy and program design
3. **Communication Standards and Media Campaign to Improve Public Attitudes Towards Autism, Promoting Equity and Inclusion:** develop a public-facing media campaign to i) promote a balanced understanding of autism as a neurodevelopmental condition that comes with strengths as well as challenges that can be disabling, and ii) introduce and model acceptable language for referring to and describing Autistic Canadians; for Accessibility Standards Canada (ASC) i) to broaden the understanding of accessibility to include language and attitudes about disability, ii) prioritize the development and implementation of standards for incorporating respectful strengths-based language related to autism into communications for adoption and iii) employ one or more Autistic experts to compile existing resources for developing such language standards.



TABLE OF CONTENTS

EXECUTIVE SUMMARY	2
BACKGROUND	7
RESEARCH AND GOVERNANCE: Members of Working Group	8
RESEARCH AND GOVERNANCE BRIEF #1: A LEADERSHIP FRAMEWORK	8
RESEARCH AND GOVERNANCE BRIEF #2: FEDERAL LEADERSHIP AND P/T ENGAGEMENT	13
RESEARCH AND GOVERNANCE BRIEF #3: RECOMMENDATIONS ON ADVISORY FOR A NATIONAL AUTISM STRATEGY	15
AFFORDABILITY AND ACCESS: Members of Working Group	19
AFFORDABILITY AND ACCESS BRIEF #1: FEDERAL DISABILITY TAX MEASURES	20
AFFORDABILITY AND ACCESS BRIEF #2: EARLY WIN OPPORTUNITY - REFORMING THE DISABILITY TAX CREDIT	23
AFFORDABILITY AND ACCESS BRIEF #3: IMPROVING ACCESS IN SOCIETY	27
AFFORDABILITY AND ACCESS BRIEF #4: FEDERAL LEADERSHIP	29
AFFORDABILITY AND ACCESS BRIEF #5: EARLY DEVELOPMENTAL INTERVENTION SERVICES FOR CHILDREN ON THE AUTISM SPECTRUM	32
EMPLOYMENT: Members of Working Group	35
EMPLOYMENT BRIEF #1: PRE-EMPLOYMENT PROGRAMS	37
EMPLOYMENT BRIEF #2: INCLUSIVE WORKPLACES	41
HOUSING: Members of Working Group	46
HOUSING BRIEF #1: INCOME SUPPORT NEEDS RELATED TO HOUSING	47
HOUSING BRIEF #2: ADDRESSING HOUSING SUPPLY CHALLENGES	50
HOUSING BRIEF #3: EARLY WIN OPPORTUNITY FOR THE NATIONAL AUTISM STRATEGY	54
INFORMATION: Members of Working Group	59
INFORMATION BRIEF #1: INTEGRATING DATA SYSTEMS	60
INFORMATION BRIEF #2: COORDINATED PROVINCIAL AUTISM PROGRAM INFORMATION SHARING	62
INFORMATION BRIEF #3: COMMUNICATION STANDARDS AND MEDIA CAMPAIGN TO IMPROVE PUBLIC ATTITUDES TOWARDS AUTISM, PROMOTING EQUITY AND INCLUSION	64



BACKGROUND

INTRODUCTION

As part of the Canadian Autism Spectrum Disorder Alliance's (CASDA) strategy to help support Canada's Federal government to implement a National Autism Strategy (NAS), CASDA and Kids Brain Health Network (KBHN) have struck Policy Development Working Groups to research information and synthesize policy options to inform the development of a NAS. The working groups are focused on 5 priority areas for Federal leadership and coordination. These 5 pillars are:

- 1. Research and Governance**
- 2. Affordability and access**
- 3. Employment**
- 4. Housing**
- 5. Information**

The aim of these working groups is to provide concise and focused policy briefs to aid the federal government to take actionable and effective steps towards the development of a NAS.

CONTEXT

On April 1, 2019, CASDA unveiled its Blueprint for a NAS. The document provides a framework for how to move forward with federal leadership to improve the lives of Autistic people and their families. It calls for the Government of Canada to "facilitate better cooperation and coordination across provinces and territories" and outlines specific initiatives related to the 5 pillars. CASDA also urges the government to launch distinct, separate Indigenous Autism Strategies. On December 9, 2019, the new Federal government announced a commitment to develop a NAS.

APPROACH

The CASDA-KBHN policy fellows each focused on a pillar and conducted an international review of Autism policies and strategies by different countries. Initial findings were presented and summarized in a webinar in Spring 2020. A call for public stakeholder engagement and consultation resulted in the formation of five working groups. Each group was composed of KBHN trainees and CASDA members (Autistics, caregivers, policymakers, service providers) from across Canada. Through consultation with other stakeholders and compilation and synthesis of research and reports over 5 months, each working group has developed recommended policy briefs (reference at the end of each brief). Additional policy briefs and briefing notes written by the CASDA team and members are also included in this compendium.



RESEARCH AND GOVERNANCE: Members of Working Group

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RESEARCH AND GOVERNANCE BRIEF #1: A LEADERSHIP FRAMEWORK

ISSUE

Currently the Federal government does not have a mechanism for cross-government coordination at the Federal-Provincial-Territorial (FPT) levels to generate shared knowledge and continuous improvement measures for public facing Autism-focused research. A structure of this kind could be activated to support Federal leadership in the development, implementation, and monitoring of a National Autism Strategy.¹

CONTEXT

The federal government has a proven track record of success with the implementation of national strategies, such as the National Dementia Strategy² and the Veterans Affairs Research, and thereby achieving national awareness of and support for these initiatives. In Bill C81, an advisory structure was created to support the development and coordination of federal programs and support for Canadians with disabilities. With respect to autism specifically, the government's commitment to the development of a National Autism Strategy (NAS) was articulated in the 2019 mandate letters of both the Minister of Health and the Minister of Employment, Workforce Development and Disability Inclusion. This was preceded by the commitment to an ASD Strategic Fund in 2018.

This brief provides three recommendations that are intended to highlight options for the successful development, implementation, and monitoring of a NAS. This strategy can unify the country in its pursuit of best practices in supporting Canadians diagnosed with autism. These recommendations are:

Recommendation #1 - Create a cross-government leadership coordinating commission

Recommendation #2 – Establish an FPT implementation framework

Recommendation #3 – Create and expand Centre's of Excellence in Autism Research

¹ It is understood that “the existing Intergovernmental Affairs Secretariat provides advice to the Prime Minister, Minister of Intergovernmental Affairs and Cabinet on federal-provincial-territorial relations, the evolution of our Federation, and national unity”. (Reference, Government of Canada website, 2020).

²Dementia National Strategy:

<https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.htm>



The above three recommendations have been developed based on extensive research³, international comparisons^{4 5 6} examination of Canada-wide commitments and community priorities, and feasible actions to support the development of a NAS.

RECOMMENDATION #1: Create a cross-governmental leadership coordinating commission.

We recommend the establishment of an independent governmental commission, such as a National Interagency Coordinating Commission of Autism. Examples of such committees exist in other countries, such as the United States.⁷

Action: (1) Identify representatives for a Federal advisory committee. (2) Establish a governance structure that includes advice on legislation and Federal activities. (3) Provide arms-length oversight and guidelines for productivity analysis and monitoring to address wide-ranging issues and challenges faced by Autistic Canadians and their families, and the communities in which they live.

Participation: Representatives from across Federal government, including, but not limited to, health, disabilities, education, finance and employment, as well as Autistic Canadians and their family members, public stakeholders and Canadian non-government organizations (NGOs), employment sectors and researchers and universities representing a variety of perspectives from within the broad ASD community.

Outcomes:

³ The All Party Parliamentary Group on Autism (APPGA) is a group of backbench members of the British Parliament and Peers interested in autism spectrum disorders. The Chair and Officers are elected by the Members of the Group at an annual AGM. [National Autistic Society](#) (Personal Correspondence: Anna Bailey-Bearfield, Policy and Public Affairs Manager, and David Mackenzie, The National Autistic Society)

⁴ The All Party Parliamentary Group on Autism (APPGA) is a group of backbench members of the British Parliament and Peers interested in autism spectrum disorders. The Chair and Officers are elected by the Members of the Group at an annual AGM. [National Autistic Society](#) (Personal Correspondence: Anna Bailey-Bearfield, Policy and Public Affairs Manager, and David Mackenzie, The National Autistic Society)

⁵ Institute of Global Health Innovation. (2016). Autism: A global framework for action. [Autism: A global framework for action - Institute of Global Health Innovation](#)

⁶ Powell, A., Parkin, E., Long, R., Kennedy, S. & Jarrett, T. (2019) Autism – overview of policy and services. Policy Briefing. [House of Commons Library](#): UK Parliament. [Autism – overview of policy and services](#)

⁷ [Interagency Autism Coordinating Committee: IACC](#): The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee that coordinates Federal efforts and provides advice to the Secretary of Health and Human Services on issues related to autism spectrum disorder (ASD). Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum. (Personal Correspondence: Dr. Susan Daniels, Executive Secretary, IACC)

- Provide guidance internally to the Federal government to provide a consistent and national approach to service guidelines for the Provinces and Territories on issues related to autism
- Inclusion of lived experience to inform government priorities and action
- Create an environment for responsive and flexible autism policy development and implementation to reflect Canada's diversity

RECOMMENDATION #2: Establish an FPT implementation-partnership framework to address program sustainability.

We recommend the development of a Federal-Provincial-Territorial (FPT) implementation-partnership framework to focus on effective, sustainable, and scalable programs and services that directly impact Autistic Canadians and their families across the lifespan.

Actions: (1) Identify FPT policy and program gaps and policy improvements to support the essential needs of Autistic Canadians. (2) Facilitate provincial, territorial, and regional collaborations in piloting new, or scaling up existing, evidence-based interventions. (3) Reduce costs, enhance resource sharing, and expand service expertise across the nation. (4) Eliminate duplication/triplication of efforts and fill identified research and governance gaps in the current fragmented system. (4) Incorporate Canadian principles of public administration in the development of policy and support programs and services for Autistic persons, with particular emphasis on accessibility, comprehensiveness and universality.

Participation: Federal, Provincial and Territorial representatives from health, the disabilities sector, education, social services, employment, Autistic Canadians, family members of those with ASD, service providers, public stakeholders and national (or Canadian) non-government organizations (NGOs).

Outcomes:

- Integration measures of regional responses on policy reform, service development and delivery, research, and dissemination of evidence-based practice principles
- Input for appropriate allocation of funds through a population segmentation approach
- Strengthen prevalence reporting of ASD that will inform an equitable distribution of basic services in relevant sectors such as health, education and social care, using a "big data" lens, or data-driven analytics, in addition to a traditional epidemiological "head count" approach
- Effective mechanisms to meet specific regional/ national needs and policy
- Accounting vehicle for systematic checks and balances for appropriate use of resources
- Canadian benchmarks for minimum standards of programs/services over the lifespan for Autistic Canadians (i.e., inclusive health, education, and social services)

RECOMMENDATION #3: Create and fund interdisciplinary Centres for Excellence in Autism Research and Care.

We recommend the creation of additional Centres for Excellence in Autism research and care where regional gaps exist, and bridging to existing Centres, to strengthen current and



prospective research, increasing capacity to inform policy through facilitation of provincial, territorial and regional collaboration. These Centres will inform, recommend and evaluate policy on lifespan aspects related specifically to autistic Canadians.⁸

Actions: (1) Establish new and support existing federally recognized **Centres for Excellence**⁹ to conduct cutting-edge research, policy analysis and evaluation to address and prioritize further policy, programs and actions needed to support the needs of Autistic Canadians and their families. (2) Set standards for the provision of interdisciplinary research and training at undergraduate, graduate, and postgraduate levels. (3) Involve autism researchers and autistic people, from the outset, working together to ensure that research is relevant to and appropriate for people on the spectrum. (5) Strengthen national and international collaborations through core funding for studentships, fellowships, and pilot projects. (6) Communicate, disseminate, and share information and research findings with a broad constituency, enabling a better and more transparent translation of research findings into practice. (7) Engage with policymakers who are charged with setting future policy to put research into practice and evaluate the impact of research findings on services and policies and the ultimate stakeholders: Autistic Canadians and their families.

Participation: Representation from existing and future national and/or regional research and training centres, understanding and respecting regional capacity, existing university research groups, and representing both official languages, Indigenous communities, and autistic leaders.

Outcomes:

- Provide a focus for researchers in Canada to expand and accelerate innovative programs and efforts to understand autism across the lifespan
- Implement national standards and guidelines through knowledge sharing and training
- Ensure oversight of regional training, policy and practice improvements through the tripartite Canada Research Coordinating Committee’s New Frontiers initiative (For example, the Transformation Fund)
- Canada’s international reputation of excellence in autism research is strengthened
- Evidence-based approaches based on scientific findings to improve services and policies for Autistic Canadians and their families

While it is recognized that disabilities warrant a strategic framework, the aim of this autism specific policy brief is to lead the development of an innovative strategy, which could eventually inform application across neurodevelopmental disability populations, leading to a pan-disability approach for Canadians.

⁸Examples of Centres for Excellence; Federally funded Networks of Centres of Excellence in Canada [Networks of Centres of Excellence of Canada](#)

⁹ In the United States, a federal structure for university centres of excellence in developmental disabilities exists since 1963: [UCEDDs](#)

RESEARCH AND GOVERNANCE BRIEF #2: FEDERAL LEADERSHIP AND P/T ENGAGEMENT

ISSUE AND RECOMMENDATION

Many programs that support Autistic individuals are delivered at the Provincial and Territorial (PT) levels. There is a lack of information sharing between the federal government and PT partners, leading to a fragmented knowledge sharing across the nation. This leads to inconsistent application of research and programs within the PT and variations of services available. Of note, there is no set of national standards on research, programs and evaluation of supports for Autistic Canadians and their families.

While we acknowledge that the Federal government has little purview over the design and delivery of the PT programs, we acknowledge the Federal government provides leadership and investment that can be coordinated, consistent and measured across all areas of support for Autistic Canadians. Therefore, we recommend an approach seeking Federal Leadership Excellence. This involves the Federal government to convene the PTs to ensure research, programs and services are delivered with the highest standards across the nation. All Autistic Canadians should receive the same high quality service in any city in Canada. This starts with the implementation of a National Autistic Strategy and a foundational step is to leverage Federal leadership and investment through a Partnership Framework between the FPTs.

RECOMMENDATION #1: Establish a Federal-Provincial-Territorial First Ministers' Meeting that includes representation from all Ministers who have any direct or indirect oversight or leadership that impacts Autistic Canadians. This includes Ministers from Health, Education, Children and Families, Housing and other relevant Ministries. This First Ministers' Meeting will focus specifically on addressing the concerns of the Autism community. The outcome of this meeting is to encourage PT collaboration that is absolutely necessary for improving support for Autistic Canadians.

In this brief, we provide actions for a First Ministers' Meeting that reflect preliminary discussion points that may guide Federal Leadership in developing a National Autism Strategy (NAS). The detailed impacts and feedback from stakeholders is represented in the accompanying policy briefs for each pillar of a proposed NAS.

ACTIONS FOR A FIRST MINISTERS' MEETING

- Confirm the range of ministerial oversight within each PT that provide support to Autistic Canadians
- Convene the Ministers and senior bureaucrats of relevant PT ministries and key stakeholders
- Encourage PTs to lay foundations for a national surveillance data set and measures that all PTs report into, including information about Indigenous populations (First Nations, Metis and Inuit) and particularly underrepresented communities (e.g. rural and remote, immigrant) (refer to Research and Governance Policy Brief and Information Policy Brief #1)
- Collaborate with the PTs to establish a high-level set of standards and guidelines to conduct research and inform consistency in service provision
- Target early intervention and diagnosis efforts that are needs based and improve equity for all through active engagement of parents/caregivers
- Enhance diagnosis portability across provinces (refer to Affordability and Access Brief #4)
- Encourage knowledge sharing across the PTs to create national standards for research and development (refer to Research and Governance Brief)
- Assess PT programs and service delivery models to maximize consistency across Canada, and implement reforms to ensure the needs of Autistic individuals and their families are sufficiently met (refer to Affordability and Access Briefs #3 and #4)
- Work with provinces and municipalities on affordable, stable rent control (see Housing Brief #2 - Income)
- Encourage PTs to implement pre-employment programs within high-schools and post-secondary institutions to improve opportunities of finding and preparing Autistic individuals for employment (see Employment Brief #1 - Pre-Employment).

As each pillar of the National Autism Strategy include actions that are relevant to a cohesive and collaborative federal-provincial-territorial partnership. The above is a summary of those actions and detailed information is provided in each brief.

RESEARCH AND GOVERNANCE BRIEF #3: RECOMMENDATIONS ON ADVISORY FOR A NATIONAL AUTISM STRATEGY

The purpose of this brief is to recommend the Federal government on the development of an advisory group for a national autism strategy representative of the autism community.

INTRODUCTION

A national autism strategy is about ensuring that all Canadians with Autism Spectrum Disorder (ASD) and their families have full and equitable access to the resources they need across their lifespan. Developing the Strategy demonstrates federal leadership and the Federal government's commitment to Canadians' right to access a continuum of quality supports throughout their lives from coast to coast to coast. This brief provides three recommendations for the Federal government regarding the development of an advisory group for a national autism strategy, considering that:

- Autism is the most common neurological condition in Canada. The National Autism Surveillance System (NASS) shows that autism spectrum disorder (ASD) has a prevalence rate of one in 66 children in Canada.¹⁰
- This data does not include Indigenous children and youth. Currently there is no data that indicates the number of Indigenous peoples living with ASD, and this population remains underrepresented. 37% of First Nations young adults (15-24) living off reserve have a disability compared to 25% of their non-Indigenous Canadian counterparts.¹¹
- Boys are four times more likely to be diagnosed with ASD than girls. Girls who meet the criteria for autism have a higher risk of not receiving a clinical diagnosis.¹² This diagnostic gender bias means that information on Autistic peoples' service needs and utilization may not reflect those of the true Autistic population.
- Caregivers from rural and remote communities experience higher out-of-pocket costs because of travel to access autism resources as well as time taken away from work.¹³

¹⁰ Ofner, M., Coles, A., Decou, M. L., Do, M. T., Bienek, A., Snider, J., & Ugnat, A.-M. (2018). *Autism spectrum disorder among children and youth in Canada 2018: A report of the National Autism Spectrum Disorder Surveillance System*. Public Health Agency of Canada.
http://epe.lac-bac.gc.ca/100/201/301/weekly_acquisitions_list-ef/2018/18-14/publications.gc.ca/collections/collection_2018/aspc-phac/HP35-100-2018-eng.pdf

¹¹ Hahmann, T., Badets, N., Hughes, J. (2019). Indigenous people with disabilities in Canada: First Nations people living off reserve, Métis and Inuit aged 15 years and older.
<https://www150.statcan.gc.ca/n1/pub/89-653-x/89-653-x2019005-eng.html>

¹² Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 56(6), 466–474. <https://doi.org/10.1016/j.jaac.2017.03.013>

¹³ Tsiplova, K., Ungar, W. J., Flanagan, H. E., den Otter, J., Waddell, C., Murray, P., D'Entremont, B., Léger, N., Garon, N., Bryson, S., & Smith, I. M. (2019). Types of services and costs of programs for preschoolers with autism spectrum disorder across sectors: A comparison of two Canadian provinces. *Journal of Autism and Developmental Disorders*, 49(6), 2492–2508. <https://doi.org/10.1007/s10803-019-03993-3>

- Immigrant caregivers experience a variety of structural, instrumental, and emotional challenges in accessing autism resources in Canada, including delays in diagnosis, fragmented and dispersed services, loss of social ties, and stigma.¹⁴
- Gender dysphoria appears to be more common in Autistic people.¹⁵ There is a need for better support, understanding, and practices for Autistic people who identify as LGBTQ+. Research on this topic remains minimal despite the high rate of LGBTQ+ people that are part of the autism community.¹⁶

CONTEXT

“Nothing about us without us” is a well-known statement from the Disability Rights Movement. In July 2019, the *Accessible Canada Act* established the Canadian Accessibility Standards Development Organization (CASDO), now known as Accessibility Standards Canada, an organization based on inclusion, consultation, collaboration, cooperation, and real input from real life experience. One of the main components of Bill C-81 is that it creates accessibility standards for regulated parties to achieve and maintain. Accessibility Standard Canada’s Board, mostly composed of people with disabilities, created these accessibility standards for the federal jurisdiction in collaboration with both the disability community and industry. It is a requirement in the bill that half of Accessibility Standards Canada’s members are people with disabilities. Accessibility Standards Canada is the first of its kind in Canada to ensure that people with disabilities have leadership in identifying standards for legislation.

Accessibility Standards Canada’s board of directors, composed of a minimum of 11 people including both the Chair and Vice-Chair, is responsible in setting the organization’s strategic direction, supervising and managing the organization’s activities and affairs, and advising the CEO on matters relating to the organization’s mandate (advising the *Accessible Canada Act*). The board of directors may also propose by-laws about Accessibility Standards Canada’s activities and affairs and appoint advisory or other committees. Directors must have Canadian citizenship or be a permanent resident, cannot be members of the Senate or House of Commons, nor can they be full-time employees in federal, provincial, or territorial public service. They are appointed by the Governor in Council to hold office on a part-time basis for, at most, four years, with the possibility of reappointment.

The CEO of Accessibility Standards Canada is also appointed by the Governor in Council and holds office on a full-time basis for, at most, five years, with the possibility of reappointment. Their responsibilities include overseeing the organization’s day-to-day operations and

¹⁴ Khanlou, N., Haque, N., Mustafa, N. *et al.* Access Barriers to Services by Immigrant Mothers of Children with Autism in Canada. *Int J Ment Health Addiction* 15, 239–259 (2017).
<https://doi.org/10.1007/s11469-017-9732-4>

¹⁵ Dewinter, J., De Graaf, H., & Begeer, S. (2017). Sexual orientation, gender identity, and romantic relationships in adolescents and adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 47(9), 2927–2934. <https://doi.org/10.1007/s10803-017-3199-9>; van Schalkwyk, G. I., Klingensmith, K., & Volkmar, F. R. (2015). Gender identity and autism spectrum disorders. *The Yale Journal of Biology and Medicine*, 88(1), 81–83.

¹⁶ Hillier, A., Gallop, N., Mendes, E., Tellez, D., Buckingham, A., Nizami, A., & OToole, D. (2020). LGBTQ + and autism spectrum disorder: Experiences and challenges. *International Journal of Transgender Health*, 21(1), 98–110. <https://doi.org/10.1080/15532739.2019.1594484>



establishing committees to assist in the development and revision of accessibility standards. In addition, a full-time member of the Canadian Human Rights Commission is appointed as Accessibility Commissioner. This person provides information or advice to the minister in the form of an annual report on issues arising from the administration and enforcement of the *Accessible Canada Act*.

RECOMMENDATION #1: Create an advisory group for a national autism strategy that models the structure of Accessibility Standards Canada.

Creating an organization with a board of directors whose majority identify as Autistic people for a national autism strategy would align an advisory group with the disability community's mantra "Nothing about us without us." The board membership of the organization will be responsible, based on their own lived experience, for setting the organization's strategic direction, managing the activities and affairs in accordance with their mandate, and, ultimately, creating the standards for Canada's National Autism Strategy. This would allow people with lived experience, Autistic people, to be in the room when it comes to communications. It would also create regulations on a national autism strategy with a disability lens that would lead to better results for Autistic people in Canada. The inclusion of Autistic people on the board would ensure fair representation for the many Autistic Canadians and their families who do not currently have a voice in autism resources standards.

RECOMMENDATION #2: Borrow from Accessibility Standards Canada's mandate to draw upon the experience and expertise of Autistic persons and their representative people, Indigenous peoples, organizations and governments, provincial and territorial governments, municipal governments, technical experts, and industry, and ensure that standards development review processes are both open and inclusive.

Borrowing from the already-established mandate of Accessibility Standards Canada for a national autism strategy advisory group would ensure that the autism community, industry (service providers), and marginalized and minority groups (rural, racialized, immigrant, gender-diverse, Indigenous) be consulted by the advisory group for the creation of the Strategy's standards.

RECOMMENDATION #3: Encourage and ensure that Autistic people and service providers who are women, Indigenous, from rural and remote communities, racialized immigrants and newcomers, and from the LGBTQ+ community be considered as members of the board of the proposed advisory panel or organization.

Encouraging people of the autism community from marginalized and minority groups to apply for board positions within the advocacy group would ensure that the views and needs of all Autistic Canadians are heard when contributing to the standards of a national autism strategy as well as ensure that no one is left behind. Parallel to Accessibility Standards Canada, the majority of directors at all times should be, as far as possible, Autistic people and reflect the diversity of Canadian society.

An advisory group modelled from Accessibility Standards Canada to serve as an expert body in the advising of a national autism strategy would ensure that Autistic people have a voice in the



development of standards, and that their lived experiences are considered in the evolution of the Strategy. By making appointments in accordance with the Government of Canada’s new approach to Governor in Council appointments, as exemplified with Accessibility Standards Canada, the Federal government supports open, transparent and merit-based selection processes that reflect Canada’s diversity. Such an advisory organization would be an embodiment of the disability community’s philosophy: “Nothing about us without us.”

Following Accessibility Standards Canada’s lead in having regulations based on standards instead of enacting regulations directly in a proposed act would ensure that regulations could be changed more fluidly over time to reflect new advances and best practices. This is important for a national autism strategy because autism is a complex issue that is everchanging. In consideration of the diversity of views on autism, it is crucial for the Federal government to create an advisory group that reflects the diversity of the autism community with minority and marginalized people as first voice in the development of a national autism strategy.

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AFFORDABILITY AND ACCESS BRIEF #1: FEDERAL DISABILITY TAX MEASURES

ISSUE

Autistic Canadians face higher costs of living, while also being more likely to be living at a low income level.¹⁷ Disability tax measures provided by the federal government are designed to address this by partially offsetting the additional costs associated with a diagnosis of a disability, including a diagnosis of Autism. Challenges associated with affordability and accessibility of these tax measures creates a barrier to much needed support. Accessing disability tax measures is a challenge for many Autistic Canadians, and financial support provided by disability tax measures is often inadequate.

CONTEXT

- Supports for Autistic individuals can vary in cost from \$26,639 to \$130,000 per person per annum.¹⁸ These high costs can make supports out of reach for Autistic individuals, particularly those that are low income.
- Individuals with disabilities report that federal disability tax measures do not provide sufficient financial support to offset the additional costs associated with their disability. For example, the current threshold on the Medical Expenses Tax Credit prevents individuals with disabilities from claiming all of their medical expenses.¹⁹
- The federal Disability Tax Credit (DTC) is one of the primary federal disability tax measures. DTC eligibility is a gateway to accessing many other disability benefits, including the Registered Disability Savings Plan and the Child Disability Benefit. Estimates from 2014 suggest that uptake of the DTC across Canada is relatively low.²⁰ Uptake rates for other federal disability tax measures, such as the Disability Supports Deduction, are also relatively low.²¹

¹⁷Autism Canada (2018). *Senate Submission, Equitable Access to Tax Fairness for the Autism Community*. Retrieved from

[https://sencanada.ca/content/sen/committee/421/SOCI/Briefs/AutismCanada\(D.Cleary\)_e.pdf](https://sencanada.ca/content/sen/committee/421/SOCI/Briefs/AutismCanada(D.Cleary)_e.pdf).

¹⁸Ontario Association for Behaviour Analysis. An Investment in Autism Will Save Ontario Millions. Retrieved from <https://ontarioautismcoalition.com/wp-content/uploads/2019/03/Invest-in-Autism.pdf>.

¹⁹Disability Advisory Committee (2019). *Enabling access to disability tax measures*. Retrieved from <https://www.canada.ca/content/dam/cra-arc/corp-info/aboutcra/dac/dac-report-en.pdf>.

²⁰Dunn, S., & Zwicker, J. (2018). Policy Brief – Why is Uptake of the Disability Tax Credit Low in Canada? Exploring Possible Barriers to Access. *The School of Public Policy Publications*, 11(2). DOI: <https://doi.org/10.11575/sppp.v11i0.43187>.

²¹Disability Advisory Committee (2019). *Enabling access to disability tax measures*.

- The number of rejected DTC applications has steadily increased over the past several years.²² Autistic individuals in particular face a high rate of rejection for the DTC.²³
- The Disability Advisory Committee (DAC) released their First Annual Report, *Enabling access to disability tax measures*, in 2019.²⁴ This report outlines many recommendations for reforming federal disability tax measures. In May 2019, the federal government publicly acknowledged the recommendations in this report, and provided an update on progress towards implementation of recommendations.²⁵

RECOMMENDATIONS

RECOMMENDATION #1: Continue progress towards implementing the recommendations outlined in the 2019 First Annual Report from the Disability Advisory Committee.

Implementing recommendations detailed in this report will lead to improvements in accessibility and affordability of disability tax measures.

- To maximize accountability and transparency, we recommend that progress updates from relevant government ministries be provided publicly on an annual basis. Updates should detail steps taken to implement recommendations, and plans for future action. Details on timelines and cross-government collaborative efforts should be included whenever possible.

The remaining recommendations in this brief and Affordability and Access Brief #2 are largely consistent with those outlined by the DAC in their initial report. Our recommendations focus more specifically on challenges faced by the Autism community, rather than those faced by the disability community, more broadly.

RECOMMENDATION #2: Reform the DTC. We recommend making modifications to the application process and the design of the DTC to make it more accessible to Autistic Canadians, and to enhance the financial support that the DTC provides. Please refer to Affordability and Access Brief #2 for a more detailed discussion on specific changes that are needed for the DTC.

²²Standing Senate Committee on Social Affairs, Science and Technology (2018). *Breaking Down Barriers, A critical analysis of the Disability Tax Credit and the Registered Disability Savings Plan*. Retrieved from https://sencanada.ca/content/sen/committee/421/SOCI/Reports/2018-06-18_SS5_RDSP-DTC_FINAL_WEB_e.pdf.

²³Canadian Autism Spectrum Disorder Alliance (2019). *Blueprint for a National Autism Spectrum Disorder Strategy*. Retrieved from <https://www.casda.ca/wp-content/uploads/2019/03/Blueprint-for-a-National-ASD-Strategy-1.pdf>.

²⁴Disability Advisory Committee (2019). *Enabling access to disability tax measures*.

²⁵Canada Revenue Agency (2019). *Government of Canada delivers on Disability Advisory Committee's recommendations*. Retrieved from <https://www.canada.ca/en/revenue-agency/news/2019/05/government-of-canada-delivers-on-disability-advisory-committees-recommendations.html>

RECOMMENDATION #3: Modify other disability tax measures to enhance financial support received by Autistic Canadians through their tax returns. Of particular focus are the Medical Expenses Tax Credit, the Disability Supports Deduction, and Childcare Expenses Deduction due to their direct ability to offset additional costs associated with Autism. We present two options for reforming these tax measures.

- **Option 1: Increase the maximum amount individuals can claim on their taxes.** Current maximums and thresholds under these tax credits do not sufficiently recognize the real costs associated with an Autism diagnosis. Increasing the amounts Autistic individuals can claim on their taxes for these tax credits can help to further offset the additional costs they face.
- **Option 2: Expand recognition of the type of expenses individuals can claim on their taxes.** Claims under the Medical Expenses Tax Credit are not consistently recognized. Autistic individuals face rejection for expenses because they are not from a pre-approved list of medical practitioners. Similar challenges exist for the Disability Supports Deduction. Amending these credits to allow all Autism-related medical expenses and supports to be claimed would improve access to financial support. These changes will eliminate the need for the federal government to continually revise and update lists of eligible expenses, and will allow novel supports to be recognized without delay.

RECOMMENDATION #4: Raise awareness for federal disability tax measures among Autistic Canadians. Distribute information about tax measures widely and in accessible formats to ensure all Autistic Canadians have the information they need to apply for and access tax measures.

- We recommend integrating information about tax measures into the diagnosis process to encourage more equitable and universal access to information.

AFFORDABILITY AND ACCESS BRIEF #2: EARLY WIN OPPORTUNITY - REFORMING THE DISABILITY TAX CREDIT

SUMMARY

- Government should commit to reforming the Disability Tax Credit (DTC), to make it more suitable for the needs of Autistic Canadians.
- Issues with accessing the DTC — including low uptake, high-rates of rejection, and red tape for families — are well-known and documented in the 2019 First Annual Report of the Disability Advisory Committee: *Enabling access to disability tax measures*.²⁶
- DTC reform offers the federal government an opportunity to demonstrate timely action towards the National Autism Strategy (NAS).
- This note makes 4 key recommendations to ensure that any reforms to the DTC meet the needs of Autistic Canadians:²⁷
 1. Replace Form T2201 with new application form(s) that better reflect the challenges faced by children and adults with neurodevelopmental conditions.
 2. Expand the number of medical practitioners able to fill out all sections of the renewed DTC application form.
 3. Recognize Autism as a lifelong neurodevelopmental condition to reduce the burden of costly reassessments and ensure Autistic adults do not lose access to their benefits.
 4. Make the DTC refundable to ensure it meets the needs of low-income Autistic Canadians.

KEY CONTEXT

- The current DTC application process does an inadequate job of accounting for people with disabilities that relate to intellectual or mental functions. The existing application process leads to Autistic individuals being rejected at much higher rates than those with physical disabilities.

²⁶ Government of Canada. 2019.

<https://www.canada.ca/en/revenue-agency/corporate/about-canada-revenue-agency-cra/disability-advisory-committee/2019-full-report.html>

²⁷ While these recommendations come from the ASD community, they are also consistent with challenges identified by a broad cross-section of the disability community and disability experts. The recommendations are targeted to ensure that the needs of the ASD community do not get lost in the process of reform.

- The result is that Autistic people are being shut out of a series of government programs they are meant to access.
- As discussed in Affordability and Access Brief #1, the DTC is an important “gateway” assessment for access to other disability programs, such as the Registered Disability Savings Plan, Child Disability Benefit, and the Canada Workers’ Benefit Disability Supplement. Despite its importance, only approximately 40 per cent of working-aged adults with a severe disability in Canada are deemed eligible for the DTC by the Canada Revenue Agency.²⁸ The barriers to approval stand to disproportionately impact Autistic people.
- Reforms to the application process could deliver immediate financial relief for Autistic Canadians and their families to address the additional costs associated with living with Autism.
- Families unfairly rejected for the DTC not only lose the tax credit, they also lose out on significant support to which they are entitled (see table below). Changes to the DTC are especially important to ensure that Autistic children benefit from the proposed doubling of the Child Disability Benefit.
- The 2020 Speech from the Throne indicated the federal government’s plan to bring forward a Disability Inclusion Plan, which will include a Canadian Disability Benefit modelled after the Guaranteed Income Supplement for seniors.²⁹

Cost of DTC Rejection for a Family with One Child Under 5 with Autism

	Disability Tax Credits	Canada Child Disability Benefits	Canada Disability Savings Bonds/ Grants	Annual Total
Median income family ³⁰	\$2,036	\$2,697 (set to double based on platform commitment)	\$3,500	\$8,233

²⁸ Stephanie Dunn and Jennifer Zwicker. University of Calgary School of Public Policy. SPP Briefing Paper Volume 11, Issue 2.

<https://www.policyschool.ca/wp-content/uploads/2018/01/Disability-Tax-Credit-Dunn-Zwicker.pdf>

²⁹ Government of Canada (2020). *Speech from the throne to open the second session of the forty-third parliament of Canada*. Retrieved from

<https://www.canada.ca/en/privy-council/campaigns/speech-throne/2020/speech-from-the-throne.html>.

³⁰ Assumes the family is in Ontario as provincial disability tax credit amounts vary. The median total income for all household types in Ontario in 2018 was \$74,600 according to the Canadian Income Survey. Assumes the family makes the RDSP contributions necessary for full matching grants.

Low-income family. ³¹	Likely zero due to non-refundable design	\$2,886 (set to double based on platform commitment)	\$1,000	\$3,886
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RECOMMENDATIONS

Autistic individuals and their families have specific needs that need to be taken into account in DTC reforms. CASDA makes the following recommendations to ensure that Autistic Canadians and their families have the supports they need:

RECOMMENDATION #1: Replace Form T2201 with new application form(s) that better reflect the challenges faced by children and adults with neurodevelopmental conditions. Form T2201 is difficult to understand, does not clearly outline expectations of medical practitioners and applicants, and is not designed to appropriately capture challenges specific to the Autism community. The 2019 First Annual Report from the Disability Advisory Committee outlines the problems with the DTC application form in great detail, particularly as it relates to the definition of mental function impairment. A more flexible definition of mental function impairment is vital and would go a long way towards capturing the communication and executive functioning challenges faced by Autistic individuals, as well the mental health aspects that are often comorbid with the disorder. The form poses particular challenges for children —expectations for functioning differ greatly between children and adults. Clinicians report significant difficulty in filling out the current application form in the context of an Autistic child, resulting in high rates of denial and time-consuming requests for additional information from CRA.

- CASDA recommends that government adopt the reformulated definition of mental functions laid out in the 2019 First Annual Report from the Disability Advisory Committee.
- Update the form’s speaking section to ‘Speaking and Communication’, allowing professionals to record deficits in social communication, as well as language and communication disorders
- Instructions for filling out this new form should be clear and in plain language to ensure that the specific requirements of the form are clearly articulated.
- We also support the report’s recommendation to develop different versions of Form T2201 for children and adults, with eligibility criteria tailored as necessary.

RECOMMENDATION #2: Expand the number of medical practitioners able to fill out all sections of the renewed DTC application form. Currently, only medical doctors can fill out all sections of the DTC form, while psychologists may only fill out the mental functions sections. The result is that Autistic individuals must often juggle and pay for multiple health professionals

³¹ Assumes the family is in Ontario as provincial disability tax credit amounts vary. The median total income for economic families in Ontario in 2018 was 101,800 according to the Canadian Income Survey. Assumes the family does not make the RDSP contributions for grants due to low income.

to complete their forms. In many cases, psychologists are the clinicians who know the individual best, providing diagnoses and supervising their supports programs. But they cannot report on motor delays and severe language disorder as part of a multidisciplinary assessment due to the restrictions to their profession. In other cases, Autistic children are not continuously or closely treated by their diagnosing clinician. Other professionals, such as Board Certified Behaviour Analysts may be better positioned to speak to a child's level of functioning.

- We recommend that registered psychologists be permitted to fill out all sections of the DTC application form, and that for children, Board Certified Behaviour Analysts also be able to fill out the forms.

RECOMMENDATION #3: Recognize Autism as a lifelong neurodevelopmental condition to reduce the burden of costly reassessments and ensure Autistic adults do not lose access to their benefits. An Autism diagnosis is for life, but despite this, Canadians are being forced to re-apply for the credit frequently (frequency varies depending on decisions by the CRA). This process is both costly and time-consuming. The wait-times to see a public sector specialist can be over 2 years, and for specialists working in the private sector, costs often surpass \$1,000 for a reassessment. Additionally, adults on the spectrum report that they are personally responsible for renewing their DTC application when they become adults. In CASDA's view, it is very costly for families to be reassessed in this manner.

- We recommend that the 'Duration' section of the form be amended to better take into account lifelong conditions. Upon initial approval, eligibility for lifelong conditions should be extended through childhood and adulthood. If re-approval is required when transitioning to adulthood, notice should be given well in advance of an individual's transition date to ensure that individuals do not lose access to their benefits. We also recommend that reapplications occur infrequently and at standardized time points.
- Reducing the need to reapply for the DTC will also reduce the administrative burden of processing frequent reapplications on the Canada Revenue Agency.

RECOMMENDATION #4: Make DTC refundable to ensure it meets the needs of low-income Canadians with Autism. Canadians with disabilities are much more likely to earn low incomes and face high levels of unemployment. People with Autism are no exception.

- CASDA agrees with numerous other Canadian stakeholder groups in recommending that the DTC be made a refundable tax credit to ensure it provides a full benefit to the many Autistic adults with low incomes.
- It will be essential for the government to consider how the shift to a refundable DTC will impact the design and delivery of the proposed Canadian Disability Benefit.

AFFORDABILITY AND ACCESS BRIEF #3: IMPROVING ACCESS IN SOCIETY

ISSUE

Through the ratification of the United Nations Convention on the Rights of Persons with Disabilities in 2010³² and the royal assent of the *Accessible Canada Act* in 2019,³³ Canada has demonstrated its commitment to making society accessible to all individuals with disabilities, with the ultimate goal of their full and equal participation in all aspects of society. At present, this goal cannot be completely realized for all Autistic Canadians, due to inconsistency in their ability to access the services and professionals that they need.

CONTEXT

- Professionals across sectors do not always have the capacity to effectively interact with and provide services to Autistic individuals. Examples in specific sectors include the following:
 - *Education*: Sixty-three percent of parents of Autistic children surveyed by the Ontario Autism Coalition in 2017 indicated that their child’s teacher did not know enough about Autism to support their learning.³⁴
 - *Senior Care*: Caregivers at retirement homes and other long-term care facilities are not always equipped to support older Autistic adults and seniors. Some Autistic individuals fear that post-retirement facilities and other supports may not have the capacity to accommodate their specific needs.³⁵
 - *Justice*: Autistic individuals have a high likelihood of interacting with the justice system, particularly those that present with aggressive behaviours or mental health issues. A Toronto study of interactions between Autistic individuals and police indicated that in 32 percent of interactions, parents reported that police involvement resulted in increased agitation of the Autistic individual.³⁶

³² Employment and Social Development Canada (2017). *The Government of Canada tables the Optional Protocol to the United Nations Convention on the Rights of Persons with Disabilities*. Retrieved from https://www.canada.ca/en/employment-social-development/news/2017/11/the_government_ofcanadatablestheoptionalprotocoltotheunitednatio.html.

³³ Employment and Social Development Canada (2019). *Canada’s first federal accessibility legislation receives Royal Assent*. Retrieved from <https://www.canada.ca/en/employment-social-development/news/2019/06/canadas-first-federal-accessibility-legislation-receives-royal-assent.html>.

³⁴ Ontario Autism Coalition (2017). *Education Issues Parent Survey Findings – Summary*. Retrieved from https://ontarioautismcoalition.com/wp-content/uploads/2017/10/4_Education-Survey-Summary.pdf.

³⁵ Autism Canada (2017). *Aging and Autism: A Think Tank Round Table*. Retrieved from https://autismcanada.org/wp-content/uploads/2018/04/AC_2017-ThinkTank_Final.pdf.

³⁶ Tint, A., Palucka, A.M., Bradley, E., Weiss, J. A., & Lunskey, Y. (2017). Correlates of Police Involvement

- Long waitlists for Autism assessments and programs across Canada preclude access to needed services and supports. A survey of a small group of pediatricians across Canada in 2018 indicated that the median total wait time for an Autism diagnosis was seven months.³⁷ Provincial and territorial Autism programs can also have long waitlists, as evidenced by the large and steadily growing waitlist for the Needs-based Autism Services in Ontario.³⁸
- Autistic individuals are more likely than the general population to experience mental health challenges.³⁹ The Canadian Survey on Disability reports that 55 percent of Autistic individuals over the age of 15 report having mental-health related challenges. Additionally, 16 percent of this population report their mental health as “excellent” or “very good,” relative to 70 percent of the Canadian household population aged 15 years and older.⁴⁰ Many Autistic Canadians report that they struggle to obtain access to the mental health supports that they need.⁴¹

RECOMMENDATIONS

RECOMMENDATION #1: Champion a comprehensive training program for professionals in a wide range of sectors to expand their capacity to work with Autistic individuals. We

recommend federal investment in a new research and training unit within the proposed Centre of Excellence in Autism Research (refer to Research and Governance Brief #1 for a more detailed discussion on the proposed Centre of Excellence). This unit expands on the previously funded Autism Research Training Program⁴² to include training programs for a variety of professionals outside of research. Funding under this unit can be directed to researchers to develop, spread, and scale training programs across sectors and jurisdictions. Particular areas of focus for professional training programs include the following:

- Reduction of stigmas and stereotypes associated with Autistic individuals.

Among Adolescents and Adults with Autism Spectrum Disorder. *J Autism Dev Disord*, 47, 2639-2647 DOI: <https://doi.org/10.1007/s10803-017-3182-5>.

³⁷ Penner, M., Anagnostou, E., & Ungar, W.J. (2018). Practice patterns and determinants of wait time for autism spectrum disorder diagnosis in Canada. *Molecular Autism*, 9(16) DOI: <https://doi.org/10.1186/s13229-018-0201-0>.

³⁸ Financial Accountability Office of Ontario (2020). *Autism Services*. Retrieved from <https://www.fao-on.org/web/default/files/publications/FA1901%20Autism/AutismServices-EN.pdf>.

³⁹ Mason, D., Ingham, B., Urbanowicz, *et al.* (2019). *A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults*. *Journal of autism and developmental disorders*. <https://doi.org/10.1007/s10803-019-04049-2>.

⁴⁰ Public Health Agency of Canada (2020). *Infographic: Autism Spectrum Disorder - Highlights from the Canadian Survey on Disability*. Retrieved from <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/infographic-autism-spectrum-disorder-highlights-canadian-survey-disability.html>.

⁴¹ Canadian Autism Spectrum Disorder Alliance (2014). *National Needs Assessment Survey For Families, Individuals with Autism Spectrum Disorder & Professionals*. Retrieved from https://www.casda.ca/wp-content/uploads/2019/02/NationalNeedsAssessmentSurvey_July-30.pdf.

⁴² Autism Research Training Program. Retrieved from <https://www.traininautism.com/>

- Education regarding diverse gender identities and mental health concerns, which are observed more frequently in the Autism community.⁴³
- Effective and inclusive communication strategies. Please refer to Information Brief #3 for a more in depth discussion of communication standards.

RECOMMENDATION #2: Prioritize mental health initiatives for Autistic individuals within existing federal funding initiatives. To date, the Strategic Autism Spectrum Disorder Fund has funded community-based programs in several provinces, some of which provide mental health support for Autistic individuals.⁴⁴ We recommend continuing to fund community-based Autism programs that include mental health support to increase access to and affordability of mental health services that understand the specific needs of the Autism community. The federal government should continue to provide regular, public-facing updates on programs that are funded through the Strategic Autism Fund. We also recommend greater transparency regarding how funding provided for mental health initiatives under health agreements with provinces and territories⁴⁵ will include support for Autistic individuals, specifically.

RECOMMENDATION #3: Introduce a national Autism waitlist reduction initiative. Waitlists for diagnosis and for provincial and territorial Autism programs provide barriers to timely access of needed services and supports. To address this issue, we recommend the federal government launch a national Autism waitlist reduction initiative. Specific elements of this initiative build on the successes of the health care waitlist reduction commitments of the *10-Year Plan to Strengthen Health Care*,⁴⁶ and include the following:

- The federal government should collaborate with provinces and territories to develop national, evidenced-based wait time targets for Autism programs, including for diagnostic services.
- The federal government should make a targeted investment in waitlist reduction to expand the capacity of provinces and territories to collect and report waitlist-related data. Improved data monitoring and reporting will enable provincial and territorial accountability to national targets.

⁴³ Warrier, V., Greenberg, D.M., Weir, E. *et al.* (2020) Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. *Nat Commun*, 11(3959). DOI: <https://doi.org/10.1038/s41467-020-17794-1>

⁴⁴ Public Health Agency of Canada (2019). *Backgrounder: New Projects under Autism Spectrum Disorder Strategic Fund*. Retrieved from <https://www.canada.ca/en/public-health/news/2019/08/backgrounder-new-projects-under-autism-spectrum-disorder-strategic-fund.html>

⁴⁵ Government of Canada (2018). *A Common Statement of Principles on Shared Health Priorities*. Retrieved from <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/principles-shared-health-priorities.html>.

⁴⁶ Standing Senate Committee on Social Affairs, Science and Technology (2012). *Time for Transformative Change A Review of the 2004 Health Accord*. Retrieved from <https://sencanada.ca/content/sen/Committee/411/soci/rep/rep07mar12-e.pdf>.

AFFORDABILITY AND ACCESS BRIEF #4: FEDERAL LEADERSHIP

INTRODUCTION

This brief expands on Research and Governance Brief #2 by outlining action items for a future First Ministers' Meeting that reflect key concerns relating to access and affordability at the provincial and territorial (PT) levels. These concerns were identified in consultation with the Autism community in working group meetings. This brief will elaborate on specific PT programs and service delivery models that need to be evaluated, and will highlight areas where better PT collaboration is required.

AFFORDABILITY AND ACCESS ACTION ITEMS FOR A FIRST MINISTERS' MEETING

- **Enhance Autism diagnosis portability across Canada** to ensure Autism diagnoses are recognized equally in all jurisdictions. This prevents the need for costly re-assessments and prevents interruptions to service access when Autistic individuals move within Canada.
- **Implement early developmental intervention services.** Refer to Affordability and Access Brief #5 for specific recommendations and action items.
- **Examine service delivery models.** PT governments should examine ways to encourage greater collaboration among professionals that support Autistic individuals and to encourage multidisciplinary approaches to service provision and care.
- **Assess PT disability income assistance programs, and implement reforms as needed.** Specific areas of focus include the following:
 - Evaluate claw back policies to ensure they are appropriate and do not create a disincentive for Autistic individuals that have the capacity to work.
 - Assess whether income provided under these programs is sufficient, particularly for Autistic adults that do not have the capacity to work.
 - Evaluate how income from disability income assistance programs interacts with income of partners and spouses.
- **Expand the capacity of PT education systems to adequately educate and provide support to Autistic children.** Specific areas of focus include the following:
 - Increasing integration of Autistic children with neuro-typical peers in the classroom setting.
 - Increasing consistency in educators' ability to create effective learning strategies for Autistic children.
 - Assessing data collection practices for educational outcomes of Autistic students to enhance PT ability to evaluate education reforms.



- **Improve PT waitlist data collection and reporting.**
 - Please refer to Affordability and Access Brief #3 for a more detailed discussion on this action item.

AFFORDABILITY AND ACCESS BRIEF #5: EARLY DEVELOPMENTAL INTERVENTION SERVICES FOR CHILDREN ON THE AUTISM SPECTRUM

ISSUE

The provision of early developmental intervention services varies across Canada, even though they are crucial for the development of all children on the autism spectrum. Children need a formal Autism diagnosis to receive these services, which often does not occur before school entry. Furthermore, there is a greater need to support child development in neighbourhoods with lower socioeconomic status (SES), as this is associated with a higher chance of developmental vulnerability. There are no mechanisms to reduce the age at which children qualify to access early intervention services, nor are these services customized according to geographic areas of need – both of which can have significant negative implications for Autistic children’s development.

CONTEXT

- The median age of Autism diagnosis remains over the age of four years, although it is possible to reliably diagnose children under the age of three years.⁴⁷
- Children experiencing functional impairments/difficulties, which may represent symptoms of Autism, but who do not have a formal diagnosis still experience developmental health challenges without having access to necessary services – which often results in:
 - Parents having to take time off work to support their children, and
 - Having to pay out of pocket for services (not feasible for low income families).
- Extensive evidence shows that it is best to begin intervention at the earliest time possible – a “wait and see” approach can have significant negative consequences for developmental trajectories of children with this disorder.^{48, 49}

⁴⁷ Canadian Paediatric Society. (2016). *Are We Doing Enough? A status report on Canadian public policy and child and youth health*. Retrieved from https://www.cps.ca/uploads/advocacy/SR16_ENG.pdf.

⁴⁸ McConachie, H., & Diggle, T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. *Journal of Evaluation in Clinical Practice*, 13(1), 120-129. DOI: 10.1111/j.1365-2753.2006.00674.x.

⁴⁹ Koegel, L.K., Koegel, R.L., Ashbaugh, K., & Bradshaw, J. (2014). The importance of early identification and intervention for children with or at risk for autism spectrum disorders. *International Journal of Speech-Language Pathology*, 16(1), 50-56. DOI: 10.3109/17549507.2013.861511.

- Many Autistic children do not have access to necessary early intervention services given the lack of these services in areas where they live – this is particularly true for rural and remote communities.
- Improving service availability in children’s neighbourhoods of residence can overcome challenges with access as they do not need to travel far for services. Neighbourhoods are defined as geographic areas consisting of dissemination blocks, with a minimum of 50 and a maximum of 600 kindergarten-aged children living in a neighbourhood.⁵⁰
- In 2018, the federal government committed to \$20 million over five years to better support the needs of Autistic Canadians as well as their families and caregivers, but none of the current projects focus on child development.⁵¹

RECOMMENDATIONS

RECOMMENDATION #1: Adopt the Enhanced 18-Month Well-Baby Visit to grant children access to early developmental intervention services.⁵² If children demonstrate developmental health challenges at 18 months, regardless of a diagnosis, a referral from the physician who completes this visit should qualify children to access necessary services.

- Currently, the Enhanced 18-Month Well-Baby Visit is only implemented in Ontario.
- **The federal government should provide guidance to the remaining provinces and territories to adopt this visit.**

RECOMMENDATION #2: Invest in sustainable linkages of population-level databases to determine the trends in prevalence and developmental health of Autistic children over time. Insights generated from these databases can help identify geographic areas of need for early developmental intervention services.

- There are several population-level databases that collect developmental health and medical diagnosis information for children, including the Institute of Clinical and Evaluative Sciences and the Early Development Instrument databases, as well as databases specific to Autistic children, such as the National Autism Spectrum Disorder Surveillance System^{53, 54, 55}

⁵⁰ Guhn et al. (2016). Examining the social determinants of children’s developmental health: protocol for building a pan-Canadian population-based monitoring system for early childhood development. *BMJ Open*, 2016(6), e012020.

⁵¹ Canadian Autism Spectrum Disorder Alliance. (2020). *Infographic: Update on the 2018 ASD Fund (published July 2020)*. Retrieved from <https://www.casda.ca/asd-fund-infographic/>

⁵² Williams, R., Clinton, J., Canadian Paediatric Society, & Early Years Task Force. (2011). Getting it right at 18 months: In support of an enhanced well-baby visit. *Paediatrics & Child Health*, 16(10), 647-650.

⁵³ Institute of Clinical and Evaluative Sciences. (2020). *ICES Data Dictionary*. Retrieved from <https://www.ices.on.ca/Data-and-Privacy/ICES-data/Data-dictionary>

⁵⁴ Early Development Instrument. (2020). *Equity from the Start*. Retrieved from <https://edi.offordcentre.com/>

⁵⁵ Government of Canada (2018). *Autism Spectrum Disorder among Children and Youth in Canada 2018*. Retrieved from



- These databases need to be sustained and leveraged for population-level database linkages to guide decision-making and resource allocation.

RECOMMENDATION #3: Coordinate a taskforce to develop a standard set of universal early developmental intervention and ensure delivery across the country. The following two actions are recommended:

- **Define a set of universal services to support children’s early development.** These universal services should be provided at the child level (early intervention services addressing all aspects of child development, school readiness programs), family level (positive parenting programs, special needs parenting programs), and neighbourhood level (inclusive schools that focus on diverse learning and developmental needs of children). Children should be eligible for these universal services even before, and certainly after, they receive their Autism diagnosis.
- **Guide the provinces and territories to provide universal services according to neighbourhood SES.** Service need varies by neighbourhood and requires customization of services.⁵⁶ In provinces and territories where low neighbourhood SES is associated with developmental vulnerability among Autistic children, the scale and the intensity of the universal services provided should be proportionate to neighbourhood-level prevalence of Autistic children, and proportion of low SES neighbourhoods in those provinces and territories.

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⁵⁶ Siddiqua, A. (2020). Social determinants of health and Autism Spectrum Disorder. [Unpublished doctoral dissertation]. McMaster University.



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EMPLOYMENT BRIEF #1: PRE-EMPLOYMENT PROGRAMS

ISSUE

Despite many individuals on the autism spectrum being able and eager to work, they face worse employment outcomes compared to their neurotypical peers and struggle to find and maintain employment.⁵⁷ In Canada, only 33% of Autistic people aged 20+ report being competitively employed compared to 79% without disabilities.⁵⁸ Additionally, 53% of Autistic people aged 20+ report obtaining their income from non-employment related sources with only 14% obtaining employment-related income.⁵³ A major cause of poor employment outcomes is a lack of suitable and accessible pre-employment services.⁵⁹ In Canada, the needs of Autistic individuals transitioning into employment outweigh the current availability of resources.^{54,60,61} We urge for a focus on inclusive pre-employment programs that support all Autistic Canadians who are newly entering the workforce to help improve the incidence of obtaining and maintaining competitive, integrated employment.

CONTEXT

- On December 9th, 2019, the federal government announced its commitment to developing and implementing a National Autism Strategy (NAS). The Canadian Autism Spectrum Disorder Alliance (CASDA) developed a blueprint⁵⁶ and roadmap⁶² to lay the foundation of what the NAS could look like in Canada.
- A focus on competitive, integrated employment is highlighted as a priority area for immediate federal action by Canadian stakeholders.⁵⁶
- Pre-employment programs were identified as a notable target area as they are a critical component of the employment support ecosystem for Autistic Canadians.⁵⁶ These programs target those individuals who have minimal-to-no work experience and are newly entering the workforce.
- Pre-employment programs are not restricted to adolescents on the autism spectrum, but instead, should be targeted towards Autistic individuals across the lifespan, of all functional and cognitive abilities, who need support developing initial workplace skills.

57 Nicholas DB, Hedley D, Randolph JK, Raymaker DM, Robertson SM, Vincent J. An expert discussion on employment in autism. *Autism Adulthood*. 2019;1(3):162-9. doi:10.1089/aut.2019.29003.djn

58 Statistics Canada. Canadian survey on disability [Internet]. 2017. Available from <https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3251>

59 Nicholas DB, Attridge M, Zwaigenbaum L, Clarke M. Vocational support approaches in autism spectrum disorder: A synthesis review of the literature. *Autism*. 2015;19(2):235–245. doi:10.1177/13623613135154

60 Nicholas DB, Zwaigenbaum L, Zwicker J, Clarke ME, Lamsal R, Stoddart KP, et al. Evaluation of employment-support services for adults with autism spectrum disorder. *Autism*. 2018;22(6):693-702. doi:10.1177/1362361317702507

61 Canadian Autism Spectrum Disorder Alliance. Blueprint for a national autism spectrum disorder strategy: how the federal government can lead [Internet]. 2019. Available from <https://www.casda.ca/wp-content/uploads/2019/03/Blueprint-for-a-National-ASD-Strategy-1.pdf>

62 Canadian Autism Spectrum Disorder Alliance. Roadmap to a national autism strategy [Internet]. 2020. Available from https://www.casda.ca/wp-content/uploads/2020/03/Roadmap-to-a-National-Autism-Strategy_CASDA_March-2020.pdf

- Having training in life skills (e.g., executive functioning, social skills, impulse management), job-readiness, and on-the-job training through pre-employment programs

RECOMMENDATION 1: Expand and enhance current pre-employment programs for all Autistic individuals across Canada.

1. Re-investing in and continuing longer-term investments of federally funded pre-employment programs to build necessary pathways for individuals on the autism spectrum newly entering the workforce (e.g., EmploymentWorks, Worktopia network) (see Table 1 for further descriptions).
 - a. International examples of successful, evidence-based, tailored pre-employment programs include ‘Steps to Success’ program in Northern Ireland and the National Autistic Society Scotland Prospects program in Scotland.
2. Ensure funded programs are evidence-based and include the following components: programs are integrated within the workforce, include mentorship components, employment skills training, life skills training, access to information and supports that extends beyond the duration of the program, and are inclusive to Autistic individuals across the lifespan of varying functional and cognitive levels.

RECOMMENDATION 2: Encourage provinces/territories to implement pre-employment programs within high-schools and post-secondary institutions to improve opportunities of finding employment and preparing individuals for employment.

1. Through programs that are supported at the federal level, prioritize having an autism-specific lens, encourage upscaling across Canada, and embedding at the high school and post-secondary levels.
 - a. CommunityWorks Canada (after school) and SchoolWorks Canada (in-school), delivered by members of the Worktopia network, is offered to students in high school.
 - b. Project SEARCH is a transition-to-work program offered to high school students.
2. Providing increased provincial/territorial funding/direction to support and expand programs at the post-secondary level.
 - a. Work Integrated Programs offered through Seneca College in Ontario.
 - b. Strengthening Transitions for Students with Autism Spectrum Disorders program, specifically, the employment services component, offered at York University and Seneca College in Ontario.
3. Ensuring that high school/postsecondary requirements of volunteer hours, co-ops, work placements, also apply to Autistic students so that they gain necessary experience.

RECOMMENDATION 3: Have sustainable autism-specific employment funding for pre-employment programs.

1. Allocating portions of pre-existing funding programs to be specific for and assist individuals on the autism spectrum entering the workforce.
 - a. E.g., Youth Employment and Skills Strategy; Opportunities Funding, Enabling Accessibility Fund.
2. Longer-term funding commitments for successful, evidence-based, proven pre-employment programs.

3. Ensuring federal labour market training agreements with provinces/territories are responsive to the needs of autistic people entering the workforce.
 - a. As part of labour management, recommend additional options for usage of funds, such as allowing individuals on the autism spectrum to receive the funding and decide on how to spend funds regarding pre-employment (e.g., selection of pre-employment programs that suit their needs).

RECOMMENDATION 4: Through sustainable autism-specific funding platforms, ensure continuous evaluation of these funded programs to ensure effectiveness and merit for sustainability efforts.

1. Coordinate program evaluations and share indicators across programs. Example indicators could include increase in competitive employment placements, job retention, connection to employment supports, wage, potential for job promotion/upward mobility.

Table 1. Autism-Specific, Federally Funded Pre-Employment Programs

Federal Program	Description	Opportunities
ProjectSEARCH	<ul style="list-style-type: none"> ● One-year transition-to-work program for youth with developmental disabilities in high school. ● Students receive classroom instruction and practical, hands-on workplace training and experience through co-op rotations. ● Includes components/training specific to Autistic youth. ● Currently running in Ontario and Manitoba. 	Provide funding at the federal level to support and increase provincial/territorial government expansion of program.
Worktopia National Employment Network	<ul style="list-style-type: none"> ● Initially funded in part by the Government of Canada (2015-2019) and under the leadership of The Sinneave Family Foundation and Autism Speaks Canada. ● Programs designed to improve employment opportunities for individuals on the autism spectrum transitioning to employment. Worktopia aims to change the odds of employment success for Autistic Canadians through meaningful opportunities that build capacity and inform policy. 	<p>Explore expansion of programs developed within the network across Canada.</p> <p>Invest in development of programs that are inclusive of Autistic individuals across the lifespan, and not just transitioning out of high school.</p> <p>Invest in and prioritize longitudinal research on pre-employment employment programs offered within Worktopia employment network.</p>
EmploymentWorks (delivered by members of the Worktopia network and currently funded under the Opportunities Fund)	<ul style="list-style-type: none"> ● Pre-employment program that offers job sampling hands-on experience, and job seeking/transition support to Autistic adults to help them obtain and maintain employment. 	Explore further expansion of program across Canada.

for Persons with Disabilities)	<ul style="list-style-type: none"> ● 12-week manualized program followed by 12-week labour market participation support. 	
CommunityWorks Canada (delivered by members of the Worktopia network and currently funded provincially)	<ul style="list-style-type: none"> ● Peer-supported pre-employment program for Autistic youth aged 15-21 in high school. ● 12-week, 30-hour duration ● Program delivered after school. ● Opportunity to acquire community volunteer experience and identify fields for future employment. 	Explore further expansion of program across Canada and discussion with provinces/territories to embed model within high school programs.
SchoolWorks Canada (delivered by members of the Worktopia Network and currently funded provincially)	<ul style="list-style-type: none"> ● Pre-employment skills development programs for autistic students still attending high school (15-21 years) ● Transition Readiness & Autism Community Employment (TRAACE) program is a 18-week provincially funded program in Nova Scotia offering pre-employment skill building modules and a volunteer work component. The students meet once a week for a 16 hour volunteer work placement. 	Explore further expansion of school-based programs in Nova Scotia and through the Calgary Board of Education.
Spectrum Advantage (currently funded through Skills Link)	<ul style="list-style-type: none"> ● Four weeks of paid job readiness classes specifically geared towards people on the autism spectrum, followed by a minimum of three months paid employment for program graduates. During the first three months of employment, both program participants and employers are supported by an ASD Employment Specialist. 	Explore further expansion of program across Canada.

EMPLOYMENT BRIEF #2: INCLUSIVE WORKPLACES

ISSUE

Despite the notable benefits that Autistic individuals bring to the workforce, such as consistency, precision, efficiency, and greater attention to detail, to name a few,⁶³ they represent a largely underutilized talent pool⁶⁴ and have worse employment outcomes (e.g., employment rate and retention) compared to those without disabilities in Canada.⁶⁵ In addition to unemployment rates, Autistic people who are employed are often underemployed, meaning that they unwillingly work part-time hours, receive minimal pay, and/or underutilize their skills in roles that are below their intellectual potential.⁶⁶ Environmental factors such as organizational culture, attitudes, supports, and policies tremendously impact, both positively and negatively, the employment opportunities and outcomes for Autistic people.⁶⁷ Thus, we urge for the creation of autism-confident inclusive workplace environments that celebrate the diversity of and break down barriers for Autistic employees across Canada. These inclusive workplace environments can also support people on the autism spectrum to develop and utilize their invaluable skills in order to obtain and maintain competitive, integrated employment.

CONTEXT

- On December 9th, 2019, the federal government announced its commitment to developing and implementing a National Autism Strategy (NAS). The Canadian Autism Spectrum Disorder Alliance (CASDA) has developed a blueprint⁶⁸ and roadmap⁶⁹ to lay the foundation of what the NAS could look like in Canada.
- A focus on competitive, integrated employment is highlighted as a priority area for immediate federal action by Canadian stakeholders.⁶³ Specifically, Canadian stakeholders recommend a focus on the creation of inclusive workplaces.⁶³

63 Hurley-Hanson AE, Giannantonio CM, Griffiths AJ. The benefits of employing people with autism. *Autism in the workplace: creating positive employment and career outcomes for generation A. Switzerland: Palgrave MacMillan; 2019. p. 257-270.*

64 Austin R, Pisano GP. Neurodiverse as a competitive advantage. *Harv Bus Rev. 2017;95(3):96-103.*

65 Statistics Canada. Canadian survey on disability [Internet]. 2017. Available from <https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3251>

66 Hurley-Hanson AE, Giannantonio CM, Griffiths AJ. The career experiences of individuals with ASD. *Autism in the workplace: creating positive employment and career outcomes for generation A. Switzerland: Palgrave MacMillan; 2019. p. 67-84*

67 Hayward SM, McVilly KR, Stokes MA. Autism and employment: what works. *Res Autism Spectr Disord. 2019;60:48-58. doi:10.1016/j.jrasd.2019.01.006*

68 Canadian Autism Spectrum Disorder Alliance. *Blueprint for a national autism spectrum disorder strategy: how the federal government can lead* [Internet]. 2019. Available from <https://www.casda.ca/wp-content/uploads/2019/03/Blueprint-for-a-National-ASD-Strategy-1.pdf>

69 Canadian Autism Spectrum Disorder Alliance. *Roadmap to a national autism strategy* [Internet]. 2020. Available from https://www.casda.ca/wp-content/uploads/2020/03/Roadmap-to-a-National-Autism-Strategy_CASDA_March-2020.pdf

- Inclusive workplaces create environments that optimize and foster development of employment-related skills and success.⁷⁰ Additionally, inclusive workplaces can provide a needed space where the strengths, skills, and diversity of those on the autism spectrum are recognized and celebrated.
- Canada has an opportunity to be a world leader by prioritizing and supporting the creation and enhancement of inclusive workplaces to enhance labour productivity and economic growth.
- This policy priority area aligns with the Pan-Canadian Strategy for Disability and Work, which highlights that Canada needs to do better at creating and fostering inclusive and diverse workplaces.⁷¹

RECOMMENDATION #1: Increase and develop employer training initiatives and opportunities for hiring and supporting Autistic employees.

1. Increasing development and dissemination of educational training and materials within Canadian businesses about hiring and having Autistic employees (e.g., educational modules, in-person/virtual training, management tips and tools, manuals)
 - a. Incorporate autism-specific training into initiatives such as the Canada-Ontario Job Grant, Opportunities Fund for Persons with Disabilities (employer awareness initiatives) and similar pan-Canadian programs.
 - b. Working with community organizations to provide training and accreditation for organizations to become autism-confident workplaces.
 - c. Model international government-funded and supported information programs such as that in Wales, titled ‘Positive About Working with Autism’ that promote beyond awareness of Autism and work to foster acceptance and celebration of Autistic employees.
2. Increase educational initiatives that center around increasing knowledge and awareness of workplace adjustments/accommodations for Autistic employees.
 - a. Many Autistic employees do not require extensive, costly adjustments/accommodations (e.g., usage of headphones). However, other Autistic employees who have multiple or dual diagnoses might require more complex supports.
 - b. For example, dissemination and implementation of the ‘Employer Toolkit’, which provides information for employers, developed in partnership with The Sinneave Family Foundation and housed within the Worktopia network website.⁷²

RECOMMENDATION #2: Commit to a workplace adjustment/accommodation fund to support employers who hire autistic individuals.

1. Create opportunities that have an autism-specific focus within the Enabling Accessibility Fund or develop similar funding opportunities that are autism-specific. This will provide

70 Nicholas DB, Zwaigenbaum L, Zwicker J, Clarke ME, Lamsal R, Stoddart KP, et al. Evaluation of employment-support services for adults with autism spectrum disorder. *Autism*. 2018;22(6):693-702. doi:10.1177/1362361317702507

71 Centre for Research on Work Disability Policy. Moving forward together: a pan-Canadian strategy for disability and work [Internet]. 2019. Available from https://www.crwdp.ca/sites/default/files/dwc_strategy_-_moving_forward_together.pdf

72 Sinneave Family Foundation. Success in the workplace: strategies from autistic employees [Internet]. 2020. Available from <https://worktopia.ca/toolkit/>

employers the opportunity to make adjustments that create an inclusive and accessible workplace for their Autistic employees.

- a. Under the Accessible Canada Act, and the commitment to establishing a Centralized Workplace Accommodation fund, ensure inclusion of employees on the autism spectrum.

RECOMMENDATION #3: Select, disseminate, and help implement best practices from federally funded programs that demonstrate effective recruiting, selecting, hiring, onboarding, and retention models used by Canadian employers to better include the needs of Autistic people; shifting from ‘one-size-fits-all’ model to competency-based hiring.

- a. Using results from the Opportunities Fund for Persons with Disabilities and Youth Employment Skills Strategy funded programs to disseminate best practices.
- b. Create cross-ministry collaborations using components of accessibility legislation to ensure employers follow and embed best-practice models of recruiting, selecting, hiring, onboarding, and retention to ensure inclusivity of Autistic individuals.

RECOMMENDATION #4: Increase access to and implementation of on-the-job supports for Autistic employees.

- a. Utilize the Accessible Technology Program (ATP) to fund development and enhancement of technological innovations specific for those on the autism spectrum at work and better promote usage of these innovations within Canadian workplaces.
 - i. Expand upon current technological innovations seen in Canada and those more newly integrated (e.g., Brain in Hand, which originated in the United Kingdom).
- b. Scale-up provincial programs to the federal level to support funding for assistive, technological devices for Autistic people in the workplace (e.g., Ontario’s Assistive Devices Program).
- c. Best-practices developed for remote work during COVID-19 pandemic should be utilized to support/promote remote work options for Autistic employees.
- d. Continue funding and enhancement of programs such as Ready, Willing, and Able that help to break down workplace barriers.
 - i. Ensure funded programs include invaluable job coaches that extend beyond new hires and have no time limit regarding access of the job coach services.
- e. Ensure proper representation of Autistic employees under the Federal Contractors Program.

RECOMMENDATION #5: Allow for and provide alternative methods of funding to support individuals on the autism spectrum in the workplace.

- a. Allow for the re-allocation of wage-subsidy funds used by Canadian employers and companies/organizations to allow for selection of workplace supports (e.g., job coaches, internal employee awareness training, hiring private employment-support agencies).

- b. Working with Revenue Canada and/or Finance Canada to discuss tax credits, deductions and/or exemptions for hiring and retaining Autistic employees.
 - i. The United States has programs that provide tax benefits for businesses who have employees with disabilities, including autism, for example, the Work Opportunity Tax Credit.

Table 1. Federal Programs and Policies and the Potential to Support Inclusive Workplaces for Autistic Canadians

Federal Programs Policies	Description (<i>specific to inclusive workplace priority</i>)	Potential Opportunities
Canada-Ontario Job Grant	<ul style="list-style-type: none"> ● Provides direct financial support to employers/organizations who wish to purchase training for their employees by third-party trainers. 	<p>Incorporate autism-specific training as part of this grant program for organizations and employers.</p> <p>Identify third-party autism-specific trainers that could support this initiative.</p> <p>Invest in similar grant opportunities across other provinces/territories.</p>
Enabling Accessibility Fund	<ul style="list-style-type: none"> ● Provide funding to projects that make Canadian workplaces more accessible for individuals with disabilities. ● Comprises three different programs: small projects, mid-sized projects, youth innovation 	<p>Ensuring eligibility criteria of grant funding is inclusive of supports needed for Autistic individuals.</p> <p>Expand inclusion of programs eligible to apply for grant funding.</p>
Accessible Canada Act	<ul style="list-style-type: none"> ● Government of Canada will foster a diverse and inclusive workforce by establishing a Centralized Workplace Accommodation Fund to support federal public service employees with disabilities. 	<p>Ensure autism-specific components of Workplace Accommodation Fund to secure supports for Autistic Canadians.</p> <p>Expand accommodation funding beyond federal public service sector.</p>
Opportunities Fund for Persons with Disabilities	<ul style="list-style-type: none"> ● Supports people with disabilities to overcome barriers to workplace participation. ● Supports employers with hiring of people with disabilities. ● Delivered by Service Canada Centres in partnership with community organizations. 	<p>Disseminate best practices from program results regarding hiring and retention models for individuals on the autism spectrum.</p> <p>Ensure call for applications to create inclusive workplaces and enhancing supports for Autistic employees.</p>
Youth Employment Skills Strategy	<ul style="list-style-type: none"> ● Government of Canada’s commitment to help young people who face barriers to employment access the information they need and 	<p>Disseminate best practices from program results regarding hiring and retention models for Autistic individuals.</p>

	<p>develop relevant workplace skills and experiences.</p>	<p>Increase funding opportunities specific for youth facing barriers, specifically those on the autism spectrum.</p>
<p>Accessible Technology Program</p>	<ul style="list-style-type: none"> • Funds innovative projects led by research institutes, private sector companies, and not-for-profit organizations to develop innovative assistive and adaptive devices and technologies to support people with disabilities. 	<p>Allocate autism-specific funding to promote development and enhancement of technological innovations specific for those on the autism spectrum at work.</p> <p>Promote usage of innovations developed through the ATP within Canadian workplaces.</p> <p>Call for technological innovations specific to supporting Autistic individuals in the workplace.</p>



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HOUSING BRIEF #1: INCOME SUPPORT NEEDS RELATED TO HOUSING

ISSUE

Many Autistic adults do not have sufficient income through employment or social assistance to live independently. Data from the Canada Mortgage and Housing Corporation (CMHC) shows Canadians with disabilities are 60% more likely to be living in Core Housing Need than people without disabilities. Core Housing Need refers to housing that fails to meet at least one of the adequacy, affordability or suitability standards, and costs a household more than 30% of its before-tax income⁷³. People with disabilities living in homes they own are one-fifth as likely to be in Core Housing Need than those who rent⁷⁴, and while homeownership may be a possibility for a minority, it is financially out of reach for most Autistic Canadians.

CONTEXT

- The median income for Autistic Canadians is just \$9675⁷⁵. Even with disability programs these individuals are almost guaranteed to be living at or below the poverty line. For example, an ODSP beneficiary receiving \$890 per month would have a total annual income of \$20,355. In most Canadian jurisdictions, this is insufficient to pay for housing at the 30% affordability standard.
- The National Housing Strategy established the Canada Housing Benefit, a \$4 billion investment starting in 2020, providing approximately \$2500 per year to up to 300,000 recipient households.
- While the RRSP Home Buyers' Plan⁷⁶ allows people to make withdrawals toward the purchase of a home without penalty, the design of the RDSP does not allow for similar withdrawals without significant penalties.

⁷³ Statistics Canada (2016). Core housing need. Retrieved 11 Aug 2020 from <https://www12.statcan.gc.ca/census-recensement/2016/ref/dict/households-menage037-eng.cfm>

⁷⁴ Canadian Association for Community Living (2020). My Home My Community: Final Report on Designing a Registered Disability Savings Plan Homeownership Plan.

⁷⁵ Berrigan, P., Scott, C.W.M. & Zwicker, J.D. (2020). Employment, Education, and Income for Canadians with Developmental Disability: Analysis from the 2017 Canadian Survey on Disability. *J Autism Dev Disord.* <https://doi.org/10.1007/s10803-020-04603-3>

⁷⁶ Government of Canada (2019). How to participate in the Home Buyers' Plan (HBP). Retrieved 11 Aug 2020 from <https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/rrsps-related-plans/what-home-buyers-plan/participate-home-buyers-plan.html>

RECOMMENDATIONS

RECOMMENDATION #1: Convene Federal/Provincial/Territorial working group to design a disability supplement to the Canada Housing Benefit. Current disability income programs are not sufficient to meet the variable housing costs across cities and provinces. Further, Canadians with disabilities have a smaller set of appropriate rental options available to them, due to additional requirements such as the proximity to their support network and other amenities. This often means a higher cost of rent.

RECOMMENDATION #2: Work with provinces and municipalities on affordable, stable rent control. We recommend calculating current rent using a sliding scale based on income, with rent never exceeding 30% of income.

- This is particularly relevant to those living in large Canadian cities with tighter housing markets which face many of the same affordable housing challenges.
- In addition to paying for housing, individuals with Autism and their families have many expenses not faced by the general population, and therefore have fewer available resources to pay housing costs.

RECOMMENDATION #3: Implement the recommendations from the Solutions Lab “Designing a Registered Disability Savings Plan Homeownership Plan”, allowing RDSP beneficiaries to withdraw funds to be used towards a downpayment for a home.

- As part of the National Housing Strategy research agenda, Inclusion Canada (formerly Canadian Association for Community Living) and People First of Canada undertook a Solutions Lab to explore options that would allow more Canadians with disabilities to achieve homeownership⁷⁷.
- Budget 2019 introduced the First-Time Home Buyer Incentive, in which the Federal Government provides 5-10% of a home’s purchase price for a down payment. RDSP funds could be similarly leveraged through this initiative.
- For people with Autism that can live independently with supports, this would give them the choice and control over where they live. Homeownership will help build wealth as a poverty reduction strategy.
- Further, the following should take place:
 1. Redefine means-testing for people with Autism, so that availability of resources, not income, is measured.
 2. Add an exemption to the 15 year payback rule for a positive means test and permit a more flexible payback schedule.
 3. Mirroring the RRSP Home Buyers Plan, add an exemption to the first time home buyer requirement and enable rollover provisions

⁷⁷ Canadian Association for Community Living (2020). My Home My Community: Final Report on Designing a Registered Disability Savings Plan Homeownership Plan.



4. Add an exemption to the one year occupancy requirement typically required for custom new housing builds
5. Define “Qualifying Homes” to require Autism-specific accessibility provisions

HOUSING BRIEF #2: ADDRESSING HOUSING SUPPLY CHALLENGES

ISSUE

Autistic individuals face housing challenges pertaining to inclusion and integration into the community, due to limited housing supply options for people with developmental disabilities, and in particular a lack of Autism-specific supports. Current housing options do not adequately account for the continuum of support needs required across the lifespan for Autistic Canadians. The Canadian Survey on Disability⁷⁸ reported 74% of people with Autism are receiving assistance with one everyday activity, and family members currently make up for the majority of these supports⁷⁹.

CONTEXT

- Housing needs for Autistics vary significantly based on the individual profile, and across the lifespan: from supportive housing with full-time care, to semi-independent living with supports, to affordable non-profit or market housing.
- The lack of supportive housing has resulted in individuals with Autism moving across the country to access services. Families and individuals with Autism should have access to appropriate and affordable housing where and when they need it.
- For Autistic adults, the transition from eligibility for childhood programs to adult services is a critical period for realizing long-term housing security. Notably, Autistic adults with an IQ over 70 but with functional limitations, often become ineligible for adult support, and often do not qualify for social assistance.
- Transitioning a young adult away from the family home is much less traumatic for the individual compared to the transition following a crisis later in life. However, for Autistic Canadians, this transition in early adulthood is not happening due to limited or no appropriate housing options.
- With appropriate housing supports being hard to find, and long waitlists for the minimal existing supportive housing options, most individuals end up unemployed, unable to attend school, and living with parents.

⁷⁸ Public Health Agency of Canada. (2017). Autism Spectrum Disorder: Highlights from the Canadian Survey on Disability.

⁷⁹ Lai, J., Dunn, S., & Zwicker, J. (2017). Improving Our Understanding of Unmet Needs Among Adults With a Developmental Disability. University of Calgary School of Public Policy 9:14.

- Research has revealed that over one-fifth of Autistic adolescents and adults have been admitted to emergency departments or psychiatric wards⁸⁰, due to a lack of appropriate community-based supports.
- The National Housing Strategy (NHS) identifies people with disabilities as a priority population to receive federal investments. While 2400 new affordable units for people with developmental disabilities is welcomed, it is insufficient given the current waitlist numbers for supportive housing. Additionally, accessibility standards outlined in the NHS must be inclusive to non-physical disabilities, including Autism and related disorders.
- The 67th World Health Assembly, regarding the topic of Autism, urged member states “to shift systematically the focus of care away from long-stay health facilities towards community-based, non-residential services.”⁸¹ Prioritizing housing models that enable individuals to live independently with supports in the community is aligned with this goal.

APPROACH

Segmenting the Autistic population into three groups would aid in developing targeted approaches that align with initiatives in the National Housing Strategy investments:

1. Those with high support needs requiring full-time care
2. Those requiring 2-6 hours a day of support, such as with meal preparation
3. Those who are living on their own, able to have a job, but need occasional help or ad hoc support to be fully included in their local community

The recommendations below aim to address the different needs within these three groups.

RECOMMENDATIONS

RECOMMENDATION #1: Direct Canada Mortgage and Housing Corporation to expand the current indicators used for inclusive housing to include persons with developmental disabilities, which is based on the framework already developed by Inclusion Canada, formerly Canadian Association for Community Living (CACL), in partnership with People First of Canada⁸², allowing for full inclusion of Autistic Canadians. In addition, based on this framework, review accessibility standards to reflect the potential needs of those on the Autism spectrum, particularly around inclusivity principles for non-physical disabilities.

⁸⁰ Lunsky, Y., Weiss, J. A., Paquette-Smith, M., et al. (2017). Predictors of emergency department use by adolescents and adults with autism spectrum disorder: a prospective cohort study. *BMJ Open* 7:e017377.

⁸¹ World Health Assembly (2014). Autism. Retrieved 31 July 2020 from https://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R8-en.pdf

⁸² Canadian Association for Community Living (2019). *My Home My Community: Conceptualizing ‘Housing Inclusivity’: A review of literature on housing, inclusion and developmental disability.*

- “Full inclusion” is defined as the degree to which a person’s home either contributes or presents barriers to their participation in the broader community. Full inclusion allows individuals to:
 - Participate in the social and economic life of their community
 - Be recognized and valued as a full member of their neighbourhood
 - Realize their rights to liberty, security of the person and equality and non-discrimination, consistent with the Canadian Charter of Rights and Freedoms
 - Live independently and be included in the community

RECOMMENDATION #2: Build connections between affordable housing developers and service agencies, to integrate principles of inclusive design into new developments.

- Primarily targeting the Group 2 segment outlined above, this might include having a full time support worker for a small group of individuals to assist with meal preparation and other activities of daily living.
- To benefit Groups 2 and 3, we recommend integrating a comprehensive suite of deeply affordable supports into housing developments.
- Develop guidelines for planners and developers involved in the planning phases of building and/or incorporating modifications to existing housing to support Autistic people, and encourage planners to consult with Autistic people in the process.
- Consider economic implications of building these design principles into new housing, compared to retrofitting existing housing for Autism-specific accessibility needs.
- Housing models should be based on the mixed-income community model and provide community integration with both individuals with developmental disabilities and neurotypicals living in the same communities.

RECOMMENDATION #3: Provide regular, public-facing progress reports on the status of improvements that meet the CACL indicator framework (see Recommendation 1), including the metric for numbers of new units built and number of new residents. This tracking should also include the number of available units appropriate for each support level.

- Additionally, we recommend mapping out service providers, by:
 - Region and/or city
 - Type of housing provided

RECOMMENDATION #4: Appoint Autistic representation to the National Housing Council. Further, engage national and provincial groups, like CASDA, to host consultations across the country to obtain direct feedback from the three groups and their caregivers on the housing needs and potential improvements.

- Bring a disability and inclusion lens to the Gender Based Analysis (GBA+) monitoring and evaluation activities outlined in the National Housing Strategy.



- Focus on continuous improvement of housing for people with Autism and other developmental disabilities as research and individual needs evolve.

HOUSING BRIEF #3: EARLY WIN OPPORTUNITY FOR THE NATIONAL AUTISM STRATEGY

SUMMARY

- Housing is a top priority for Canadians with Autism, but the community's needs are unrecognized and underserved in policy.
- The government has committed in mandate letters to a National Autism Strategy (NAS). The community has identified housing as a critical pillar of a strategy.
- There are clear areas for alignment between a NAS and the National Housing Strategy (NHS). The NHS identified people with disabilities as a priority population to receive support from NHS investments.
- New models and greater awareness of Autism-specific housing needs are needed to lead the way toward long-term investments.
- Government can start 'building out' the NAS housing pillar today by leveraging existing NHS innovation and research investments.
- As a first step, CASDA has identified specific opportunities to better target existing initiatives to respond to the needs of Autistic Canadians.

KEY CONTEXT

- People with Autism often struggle to find housing options that are affordable and meet their needs. Shortages of housing supports for people with disabilities generally are compounded by a lack of Autism-specific supports.⁸³
- Because Autism is a spectrum disorder, housing needs can vary considerably based on the individual — ranging from supportive housing to affordable independent living in non-profit and market housing.
- For people with Autism that need supportive housing, some face extremely long waitlists in their home communities (in some cases more than 20 years) with acute challenges in both urban and rural areas. Because of restrictive eligibility rules, Autistic Canadians often find themselves ineligible for the supportive housing that does exist.

- The Ontario Ombudsman has pointed to the consequences of these gaps — Autistics with high needs ending up in unacceptable situations, including psychiatric hospitals, nursing homes, shelters, and jails.⁸⁴
- The NHS commitment to a minimum of 2400 new units for people with developmental disabilities is welcome, but not enough. It is not clear that a general approach to developmental disabilities will be responsive to the varied and distinct needs of people with Autism. For example, group homes can be challenging for people with sensory sensitivities. People with Autism may benefit from environments that provide social support but are better designed to account for these challenges.

OPPORTUNITIES FOR ACTION

- Over the long-term, much more significant policies and investments are needed to expand the housing options available to Canadians with Autism.
- In the short-term, CMHC should consider how to leverage its existing investments in the NHS to support the goals of a National Autism Strategy and create greater knowledge and awareness of the housing challenges facing Canadians with Autism.
- The National Housing Strategy includes \$241 million over 10 years in investments in housing research and innovation. In our initial scan of existing NHS innovation and research investments, CASDA has identified several opportunities where CMHC could make housing options for Canadians with Autism a priority:
 - **NHS Demonstrations Initiative:** Call for Autism-specific proposals (in tandem with or after current open call).
 - **National Housing Conference:** Use a conference session to highlight Autism housing issues/need for an affordable housing project pipeline that meets the needs of people with Autism.
 - **NHS Research & Planning Fund:** Identify research related to Autism & housing needs as a priority area for 2020/2021.
 - **Housing Needs Data:** Partner to develop comprehensive data on diverse housing needs for Canadians with disabilities and work to ensure an Autism lens is incorporated.
 - **Solutions Labs:** Work to develop a coalition of Autism and housing stakeholders to submit an application to Lab.
- To ensure ongoing federal policies are responsive to the needs of Autistic Canadians, CMHC can also work with the National Housing Council and Federal Housing Advocate to identify opportunities to investigate systemic housing challenges faced by people with Autism and ensure policies are informed by lived experience.

Table 1: NHS Innovation & Research Streams and Potential for Autism Focus

Program	Description	Potential for Autism Focus	Key Dates & Opportunities
<p>NHS Demonstrations Initiative</p>	<ul style="list-style-type: none"> ● Provide a demonstration platform to showcase innovative technologies, practices, policies, programs and strategies in the affordable housing sector that are aligned with the priority areas and vulnerable populations of Canada’s NHS ● Focus is on showcasing and building awareness, knowledge and acceptance of promising innovations ● Project support of \$25k up to \$250k, up to 18 months 	<p>High</p>	<p>Current status: Open call for applications, due July 24, 2020</p> <p>Potential opportunities: Call for Autism-specific proposals (in tandem with or after current open call)</p> <p>Identify housing innovations for people with Autism as a priority in current round application materials and scoring</p>
<p>Solutions Labs</p>	<ul style="list-style-type: none"> ● Provides housing stakeholders with funding and expert innovation lab consultants to help solve complex housing problems using innovation methods and tools ● Will support labs ranging in duration from 1-3 days lab sprints to longer-term labs of up to 18 months. Projects support of \$25k up to \$250k 	<p>Medium</p>	<p>Current status: Open call for applications, due March 20, 2020</p> <p>Potential opportunities: Coalition of Autism and housing stakeholder(s) to submit application to lab</p> <p>Micro-grant to support development of solutions lab proposal</p>
<p>Collaborative Housing Research Network</p>	<ul style="list-style-type: none"> ● Supports enhanced research under Canada’s National Housing Strategy ● Joint initiative between CMHC and the Social Sciences and Humanities Council ● Available to researchers at post-secondary institutions in partnership with 	<p>Low</p>	<p>Current Status: Applications closed (Stage 2 – by invitation only), funding seems to be earmarked to end of 10 year NHS</p> <p>Potential Opportunities: Explore for potential Autism lens in Stage 3 of project, or partnerships in next iteration of NHS</p>

	community organizations/NFPs, etc.		
NHS Research & Planning Fund	<ul style="list-style-type: none"> Provides funding for NFPs and NGOs (housing providers, charities, Indigenous governments/organizations, etc.) to undertake housing-related research or research planning activities Will fund up to 75% of program costs (up to \$100k for individual projects, \$250k for a research program, \$50k for a planning or knowledge mobilization project); duration of up to 2 years 	High	<p>Current Status: Applications closed</p> <p>Potential opportunities: Identify research related to Autism & housing needs as a priority area for 2020/2021</p>
CMHC Housing Research Scholarship Program	<ul style="list-style-type: none"> Provides financial assistance to post-doctoral fellows undertaking housing research through partnerships with the Canadian Institutes of Health Research, the Social Sciences and Humanities Research Council, and the Natural Sciences and Engineering Research Council \$3.65 million is available 	Low	<p>Current Status: Currently closed</p> <p>Potential opportunities: Encourage applications from individuals working on housing needs for individuals with neurodevelopmental disorders</p>
Housing Research Awards	<ul style="list-style-type: none"> Recognize world-class housing research being conducted in Canada and provide funding for research teams to promote and expand their work 	Low	<p>Current status: Open March 2020-03-04</p> <p>Potential opportunities: Encourage focus on meeting housing needs of Canadians with disabilities and especially neurodevelopmental disorders</p>
National Housing Conference	<ul style="list-style-type: none"> Showcase new ideas and innovations in affordable housing at an annual, multi-stream conference 	High	<p>Current status: Annual, next conference: May 12-13, 2020</p> <p>Potential opportunities:</p>

			Use conference session to highlight Autism housing issues/need for affordable housing project pipeline that meets the needs of people with Autism
Housing Needs Data	<ul style="list-style-type: none"> • Works with a wide range of partners to identify, communicate and fill data gaps to better understand housing conditions. • Focuses on the housing needs of Canada’s most vulnerable populations. • Increases the ability to develop housing policy in anticipation of changing housing needs, conditions and market forces. 	High	<p>Current status: Unclear, ongoing</p> <p>Potential opportunities: Partner to develop comprehensive data on diverse housing needs for Canadians with disabilities and work to ensure an Autism lens is incorporated</p>
Expert Community on Housing (ECOH)	<ul style="list-style-type: none"> • A collaborative, online network of housing experts for sharing housing knowledge and contributing to the development of housing solutions. • Applicants to all Innovation and Research programs are encouraged to be part of this network 	Low	<p>Current status: Open to applications, ongoing</p> <p>Potential Opportunities: Work to raise awareness of Autism housing needs within community</p>
Affordable Housing Innovation Fund	<ul style="list-style-type: none"> • \$200 million fund to encourage new funding models and innovative building techniques in the affordable housing sector 	Medium	<p>Current status: Next call for applications 2020</p> <p>Potential Opportunities: Call for Autism-specific proposals</p>



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INFORMATION BRIEF #1: INTEGRATING DATA SYSTEMS

ISSUE

The lack of data standardization and linking precludes the necessary complex analyses that could lead to significantly more efficient targeted care, and innovative environmental and policy modifications. As a result, Canada is far from achieving the improvements to quality of life for Autistic individuals and their families, and the benefits to Canada from greater inclusion and realizing individuals' unique talents and productivity potential, which could be possible with the data that is available.

Obesity is a well known example of a health condition whose complexity has forced the adoption of more sophisticated thinking and integrated multi-system approaches to address it. Autism, meanwhile, is a neurodevelopmental condition associated with challenges that are at least as complex to address. This complexity is partly due to the variation in how autism manifests from person to person, which corresponds to widely varying needs and supports over the lifespan.

Designing individualized programs to address unique constellations of autism-related problems for each individual requires evidence that current research approaches are not equipped to produce. The critical limitation is the lack of a data system that integrates data from the multiple systems of care that Autistic individuals and their families interact with. The abundant data on each individual currently exists in silos—scattered across clinical organizations, community organizations, provincial-and-territorial (PT) administrative databases, and large research cohort databases.

CONTEXT

- The idea and vision of a Learning Health System—defined by the US Institute of Medicine as a process where “science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families active participants in all elements, and new knowledge captured as an integral by-product of the care experience”—is becoming increasingly popular for its potential to achieve “care that is safe, effective, patient-centered, timely, efficient, and equitable”⁸⁵. The autism and child disability research community and related service organizations, specifically, are becoming increasingly aware and enthusiastic of this vision. Innovative-minded representatives from these groups are likely to welcome action that encourages the sharing and integration of data they control to support it.
- McMaster University and the Azrieli Foundation have partnered to generate an actionable roadmap towards a national learning health system for neurodevelopmental disorders including autism, which will be based on the best available research evidence and insights from systematic

⁸⁵ Institute of Medicine (US) Committee on Quality of Health Care in America. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington (DC): National Academies Press (US).



stakeholder engagement, and which will enhance coordination and integration of research, policy, and care on a national scale.

- CASDA is well-positioned to coordinate community organizations across the country to be involved and linked with research assets.
- Some federal surveillance-related data collection initiatives rely on PT data sources—the Public Health Agency of Canada’s (PHAC) report on the National Autism Spectrum Disorder Surveillance System⁸⁶ is one example. Standardizing relevant data elements across PT administrative databases would allow for more efficient and complete federal reporting. Standardizing even these limited data elements could catalyze broader national efforts (led by PT policy makers, researchers, and other stakeholders) to integrate data systems across PTs, contributing to the realization of the vision of a learning health system.
- Early progress toward a Learning Health System framework would allow for easier cross-PT analyses of relevant programs and services, and potentially lead to less variation across PTs. It would also help achieve care principles that are increasingly recognized as essential ingredients of PT autism programs, such as the following: integrated (collaborative, cross-disciplinary) care, strengths-based care, family-centered care (empowering families to care for the child), and family support (including navigation support, peer support, mental health support).

RECOMMENDATIONS

We believe the federal government can begin to play a limited but effective role in encouraging PTs to take early steps to lay the foundations for a learning health system for autism by taking the following actions:

RECOMMENDATION #1: Provide research and other relevant grants to incentivize the study of administrative databases for each service system (Education, Social, Health) across PTs to identify strong models for PTs to follow in terms of minimal data elements, cross-linking to other databases (including those of other PTs, clinical organizations, community organizations, and large research cohorts), and other standards required for a Learning Health System. Products of the research should include partnerships with PT stakeholders to promote uptake of the study’s findings, and a report for policy makers in relevant PT ministries.

RECOMMENDATION #2: Set PHAC-recommended minimum data elements (data standards) for Education and other service systems, for PTs to include in their respective administrative databases, to support the needs of ongoing or projected federal data collection initiatives such as the PHAC National Autism Spectrum Disorder Surveillance System.

⁸⁶ Ofner, M., Coles, A., Decou, M., Do, M. T., Bienek, A., J Snider... - Public Health Agency of Canada, 2018. (n.d.). Autism spectrum disorder among children and youth in Canada 2018: a report of the National Autism Spectrum Disorder Surveillance System.

INFORMATION BRIEF #2: COORDINATED PROVINCIAL AUTISM PROGRAM INFORMATION SHARING

ISSUE

There is a lack of service system information and research knowledge exchange regarding autism among provincial and territorial (PT) governments, creating a risk when policymakers design policy or make decisions that affect Autistic Canadians. Gaps created by this lack of sharing have led to divergent language regarding services and supports, inconsistent service delivery models, and redundancy and inefficiency as the PTs conduct their own research in isolation from each other to inform changes to autism services and supports.

CONTEXT

- P/T ministries conduct their own valuable research, involving stakeholders and experts in monthslong processes, and resulting in information-rich documents that are often relevant not just to their own programs, but to those of other provinces—for example, The Ontario Autism Advisory Panel Report⁸⁷, developed by a 20-member Advisory Panel to inform development of the province’s autism program for the Ministry of Children, Community and Social Services. Despite their relevance and usefulness, bureaucrats and politicians from other provinces usually only hear about such documents haphazardly through word or mouth.
- Other policy-relevant research, such as citizen surveys, remain confidential even though their findings may often be useful to other service organizations within a PT, or ministries and organizations in other PTs.
- The Autism and Intellectual Disability Knowledge Exchange Network (AIDE Canada) has produced an information resource that lays out how autism services are organized in each PT (<https://aidecanada.ca/learn/resources/under-18-supports>⁸⁸). Keeping such information up-to-date is a challenge, however, as provincial policy and program organization is often unstable. Moreover, it is not in AIDE’s mandate to provide information about the research done by relevant ministries across PTs, which would be more useful to autism program designers and policymakers across Canada.

RECOMMENDATIONS

⁸⁷ Ontario Ministry of Children, Community and Social Services. (2019). The Ontario Autism Advisory Panel Report - October 2019, 1–64.

http://www.children.gov.on.ca/htdocs/English/documents/specialneeds/autism/AutismAdvisoryPanelReport_2019.pdf

⁸⁸ AIDE Canada. Autism-Related Funding Under 18 (By Province).

<https://aidecanada.ca/learn/resources/under-18-supports>



RECOMMENDATION #1: We recommend the Public Health Agency of Canada fund a gap analysis to determine information needs of PT policymakers to make decisions relevant to autism policy and program design (e.g. information about organizations and what they do, what other provinces are doing and the research and rationale for their policies and program design decisions, and what is or is not working).

RECOMMENDATION #2: We recommend that the findings from this gap analysis be used to inform what resources the federal government can create or encourage (incentivize) to fill this gap, and what role the federal government can take in coordinating the PT governments to use and share their knowledge and experience.

RECOMMENDATION #3: We recommend the Federal Government convene a session, for example, at a Canadian Autism Leadership Summit, inviting ministers and senior bureaucrats of relevant PT ministries involved in providing autism services (e.g., Education, Social, Child, and Health services), alongside various stakeholders to build a collaborative framework of intergovernmental partnership in sharing knowledge and resources regarding autism. Desired outcomes would be a plan to initiate ways of sharing knowledge among PTs, establish a common lexicon for describing autism policy and programs, and design a common service standard across the country as well as setting future goals and a process to follow up occasionally.

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INFORMATION BRIEF #3: COMMUNICATION STANDARDS AND MEDIA CAMPAIGN TO IMPROVE PUBLIC ATTITUDES TOWARDS AUTISM, PROMOTING EQUITY AND INCLUSION

ISSUE

Deficit-based and ableist language from the past has become unacceptable today because it perpetuates devaluing and discriminatory attitudes to autism and related disabilities. Persistence and pervasiveness of such language and attitudes is a key cause of marginalization of Autistic people. Negative attitudes among many Canadians can be subconscious, but they limit access to critical aspects of life such as employment and housing, preventing full and equitable participation in Canadian society. There is a corresponding cost to Canada from the lack of access and participation by our Autistic population, which has significant unrealized talent and skills to contribute. Language needs to change to increase accessibility and inclusion for Autistic Canadians.

CONTEXT

- The World Health Organization, noting that Autistic people “face barriers in their participation as equal members of society, and reaffirming that discrimination against any person on the basis of disability is inconsistent with human dignity,” has urged member states to support “public awareness-raising and stigma-removal campaigns consistent with the Convention on the Rights of Persons with Disabilities.”⁸⁹
- In its Blueprint for a Canadian National Autism Strategy, CASDA has made the recommendation to “create awareness strategies to promote inclusion for Autistic Canadians,” which was followed, in its Roadmap, by the proposal for an “awareness/public education campaign to promote understanding and inclusion.” The Autistic self-advocate community feels that any such campaign should promote acceptance, not just awareness.
- Currently, there is abundant social research literature (e.g., Bottema-Beutel et al.⁹⁰, below), general awareness within the autism community, and available language guides (e.g., published

⁸⁹ World Health Organization. (2014). Sixty-seventh World Health Assembly: Autism (WHA67.8, Agenda item 13.4) (pp. 1–4). Retrieved from https://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R8-en.pdf

⁹⁰ Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2020). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood*, aut.2020.0014–12.
<http://doi.org/10.1089/aut.2020.0014> <https://www.liebertpub.com/doi/pdf/10.1089/aut.2020.0014>

by CASDA⁹¹, Autism Canada⁹², below) to both justify and support more positive messaging around autism and related disability.

- One of the mandates of Accessibility Standards Canada listed in its Departmental Plan⁹³ is “sharing information about identifying, removing and preventing accessibility barriers.” From the perspective of the Autistic self-advocate community, language is a key accessibility barrier for reasons described above.

RECOMMENDATIONS

RECOMMENDATION #1: We recommend the Public Health Agency of Canada develop a public-facing media campaign to i) promote a balanced understanding of autism as a neurodevelopmental condition that comes with strengths as well as challenges that can be disabling, and ii) introduce and model acceptable language for referring to and describing Autistic Canadians.

RECOMMENDATION #2: We recommend that Accessibility Standards Canada (ASC) i) broadens the understanding of accessibility to include language and attitudes about disability; ii) prioritizes the development and implementation of standards for incorporating respectful strengths-based language related to autism into communications—for adoption by all federal departments, and by stakeholders ASC engages to promote accessibility; and iii) employs one or more Autistic experts to compile existing resources for developing such language standards. ASC may see adoption of these recommendations as helpful to mitigate the risk of “lack of credibility,” which it identified as something it “needs to quickly establish” in its 2020 to 2021 Departmental Plan.

RECOMMENDATION #3: We recommend that similar language standards and messaging be incorporated into training about autism for frontline (public-facing) federal service professionals, especially those who may come in contact with Autistic people (e.g., RCMP).

RECOMMENDATION #4: We recommend that the Public Health Agency of Canada update and revise its statement on Canada’s Autism Awareness Month (October)⁹⁴, renaming it to “Autism Acceptance Month.” This would reflect consensus that awareness in itself is not always positive from the perspective of the Autistic self-advocate community, whereas acceptance is.

⁹¹ Canadian ASD Alliance Language Guide. CASDA; June, 2020.

<https://www.casda.ca/wp-content/uploads/2020/07/CASDA-Language-Guide-7.pdf>

⁹² Jackie McMillan, Jessica Pigeau. Words matter: A collaborative language and communication guide in the autism field. Autism Canada; September, 2016.

https://autismcanada.org/wp-content/uploads/2015/04/AC_LanguageDocument-2016-1.pdf

⁹³ Accessibility Standards Canada 2020 to 2021 Departmental Plan.

<https://www.canada.ca/en/accessibility-standards-canada/corporate/reports/departmental-plan/2020-2021.html#h2.4>

⁹⁴ Public Health Agency of Canada. Autism Awareness Month – October [Statement].

<https://www.canada.ca/en/public-health/news/2018/10/ministerial-statement-autism-awareness-month--october.html>



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INFORMATION BRIEF #3: APPENDIX - DISTINGUISHING THREE TYPES OF INFORMATION IN POLICY

In any conversation about information, there needs to be clarity and distinctions made between the use of information that is

- 1) Derived or based on evidence and used for varied purposes (knowledge translation; e.g., for public awareness, family education, professional training, guidance of clinical or professional practice; see blue circle 1, below),
- 2) In data form and has the potential to generate research knowledge or care system improvement (e.g., surveillance, clinical, non-profit organization, or research cohort databases; see blue circle 2, below), and
- 3) Intended to support system access and navigation by care users (e.g., navigation information for caregivers or Autistic people; see blue circle 4, below).

