



Submission to Standing Committee on Health in regards to its study on children's health on behalf of Autism Alliance of Canada

About Autism Alliance of Canada

Representing over 600 organizations and individuals, Autism Alliance of Canada (formerly CASDA) is committed to ensuring the creation and implementation of a comprehensive National Autism Strategy that addresses critical gaps in funding and policies, which are preventing Autistic individuals and their families from exercising their equal rights as Canadians.

Background

Autism is the most common neurological disability in Canada with most recent estimates stating that one in fifty Canadian children are on the autism spectrum, a lifelong neurodevelopmental condition. Pan-Canadian data [published in 2022](#) suggests that an estimated 2% of Canadian children and adolescents are Autistic.

Autistic Canadians and their families face barriers to full and equal participation in society and have a high degree of unmet need. This population is at higher risk for many concurrent medical and psychiatric conditions, and have more complex health needs compared to the general population. The majority of Autistic people require services across their lifespan, and these services may originate from the health, social and/or educational systems. In Canada, these systems are not structured or aligned to support the complex and ongoing needs of Autistic persons and their families. There are significant gaps in knowledge in fundamental issues of relevance to the care and support of Autistic people nationally. National leadership is urgently needed to ensure the basic human rights of Autistic people are being met in Canada.

Over 14 years ago, Autism Alliance of Canada began calls for a National Autism Strategy after the release of the “Pay Now or Pay Later: Autism Families in Crisis” report brought forward by the Senate in 2007. As a result of our advocacy over many years, the federal government committed to the development of a National Autism Strategy in 2019. In 2021, the Senate of Canada passed Bill S-203, “An Act respecting a federal framework on autism spectrum disorder.” The proposed legislation echoes the concerns expressed by Autism Alliance of Canada and their members, and calls upon the federal government to act on “Pay Now or Pay Later,” the Senate report published in 2007. The Bill has now proceeded through first reading in the House of Commons.

As a result of our advocacy, the Public Health Agency of Canada is currently leading the development of the National Autism Strategy. A strategy still is not developed - though mandated by the current government - and there are many competing priorities in the political agenda. While we are one step closer to the development of a National Autism Strategy, there is much work to be done. As the NAS comes together, our organization and our members will continue to have a significant role to play in order to address priority areas within the sector in the years to come for the Autistic community and other equity-seeking groups.

Our Position

Autism Alliance of Canada is supportive of a Federal Child Health Strategy that has a strong, focused and targeted approach to supporting disadvantaged and marginalized children in Canada - including those diagnosed on the autism spectrum. A Federal Child Health Strategy for Canada should establish targeted outcomes that prioritize equity, inclusion and accessibility.

The goals set out for the proposed Federal Child Health Strategy include:

- Securing the basics of life (access to reliable income, food security, housing, safe environment, clean water, learning and literacy, developmental support, childcare and internet)
- Accessible mental health services (easily navigated and designed to support the unique needs of each child, youth and family)
- Feeling love and a sense of belonging, and having opportunities for unstructured leisure and play (includes access to outdoor recreation and green space)
- Racial, gender and structural equity (fully engaging with racial justice and gender equity)
- Their voices being heard (children, youth and families cannot flourish if they feel their voices are not heard, and if they have no hope for their future)

It is important to note that none of the above targets are currently being accomplished for children on the autism spectrum in Canada.

Recommendations

Autism Alliance of Canada positions that a Federal Child Health Strategy should function as an enabling mechanism for the development of targeted strategies to support equity-seeking groups including children on the autism spectrum, those with other neurodevelopmental disabilities and other 'invisible' disabilities. A Child Health Strategy should prioritize addressing intersectionality and be informed by, and align with, the current development of a National Autism Strategy. Both Strategies should reflect the need to:

- Adopt inclusive policy design that centers the perspectives of Autistic people living in Canada;
- Improve the understanding and acceptance of autism and neurodevelopmental disabilities in Canada;
- Provide timely access to screening, diagnosis and post-diagnostic services;

- Define minimum standards of support (programs and services) and access to professionals across Canada to ensure that children on the autism spectrum receive equitable access to supports, regardless of their postal code;
- Provide guidance to the provinces and territories to implement evidence-informed models of supports that can be delivered and accessed across the country;
- Improve access to educational supports for children on the autism spectrum;
- Improve access to mental health supports for children on the autism spectrum;
- Support the transition to adolescence and adulthood;
- Strengthening the financial support for caregiving for families with children with disabilities and support long term financial planning for children with disabilities.

Federal strategies should result in increased multi-ministry and intergovernmental partnership and deeper cooperation between federal and provincial governments to deliver critical health, education and social services to children on the autism spectrum and particularly those who are part of equity-seeking groups.

REFERENCES:

Blueprint for a National Autism Strategy (2019):

<https://www.autismalliance.ca/wp-content/uploads/2019/03/Blueprint-for-a-National-ASD-Strategy-1.pdf>

Roadmap to a National Autism Strategy (2020):

https://www.autismalliance.ca/wp-content/uploads/2020/03/Roadmap-to-a-National-Autism-Strategy_CASDA_March-2020.pdf

Policy Compendium (2020, 2021)

<https://www.autismalliance.ca/policy-compendium/>