

Frequently Asked Questions – National ASD Strategy

Context

The Canadian ASD Alliance (CASDA) is continuing its call for a National ASD Strategy by launching a Blueprint for a National Autism Spectrum Disorder Strategy. This document provides information on common questions you might receive when speaking to people about the Blueprint.

Why do we need a strategy?

Autism spectrum disorder (ASD) is the most common and fastest-growing neurodevelopmental disorder in Canada, affecting 1 in 66 Canadians aged 5-17 and an estimated 500,000 people and their families nationwide. Without appropriate supports that fit their needs, people with ASD and their families see drastically worse health, education, employment and quality of life outcomes. These effects ripple throughout their communities. We need to do better.

We need a strategy that drives real action to make sure all Canadians with ASD and their families have full and equitable access to the resources they need across a lifespan where and when they need them. A National ASD Strategy should identify the full range of needs of the community, across Canada. We need a wide range of policy makers and community stakeholders working together to get positive results.

Why now? Why CASDA?

CASDA was formed as the autism community's response to the 2007 Senate report [Pay Now or Pay Later: Autism Families in Crisis](#). We are committed to ensuring the implementation of a National ASD Strategy to ensure all Canadians with ASD and their families have full and equitable access to the resources they need across a lifespan where and when they need them.

CASDA has been advocating for a National ASD Strategy for 12 years. The ASD community cannot afford to wait any longer. Families are being pushed to the breaking point. Canadians with ASD have a right to equal access to health care and education that meets their needs and to participate fully in society.

In April 2019 (World Autism Awareness Month) we launched a revitalized campaign for a National ASD Strategy with a Blueprint for change. As we head towards an election this fall, we are calling on all federal political parties to commit to a National ASD Strategy that delivers on the vision of this Blueprint.

About the Blueprint

What is CASDA's vision of a National Autism Strategy?

The Blueprint for a National ASD Strategy is broken down into six key principles and 3 key areas of focus:

The six key principles call for the strategy to be:

- Person-centered, reflecting needs over a spectrum and lifespan
- Inclusive of pan-Canadian stakeholders
- Co-designed with first-person perspectives: *nothing about us without us*
- Include a separate co-designed Indigenous approach
- Culturally responsive and appropriate, especially for vulnerable Canadians
- Reflective of different regional needs, especially northern, rural and remote communities

The three areas of focus are:

1. Federal leadership to guide and encourage coordinated and collective change through pan-Canadian knowledge exchange and dissemination.
2. Immediate federal leadership in areas in federal jurisdiction:
 - affordability and access;
 - information;
 - employment;
 - housing; and
 - research
3. A federal cross-government approach to ASD that ensures action is coordinated across ministries, agencies, policies and programs.

Where do the voices of autistic Canadians fit in to the National ASD Strategy?

In developing the Blueprint, CASDA drew on what we learned from:

- The [National Needs Assessment Survey](#), which had 5000 respondents, 61% of whom were either Autistic Canadians or their family members.
- The [Canadian Autism Partnership Project](#), which was led by a working group of experts including seven self-advocates, and involved consultation with 5000 Canadians, of which 75% were family members or Autistic individuals.
- Our annual [leadership summit](#), which has over 200 participants per year from CASDA's membership.
- Advice from leading ASD experts in the CASDA community, including self-advocates.

Is the Blueprint the National ASD Strategy? What about needs and priorities that the Blueprint does not cover?

The Blueprint presented by CASDA is intended as a building block for a National ASD Strategy. It was created to help secure a commitment from the federal government to develop a comprehensive National ASD Strategy. It is not meant to be the final word.

We are advocating for the federal government to launch a deep, wide and robust consultation with the ASD community to validate what a National ASD Strategy should include. Partnership with the ASD community is vital to this process and anchored in the principles of the Blueprint.

How much will this cost?

The Blueprint recommends different actions, some of which carry no direct cost. For others, more work would be needed to estimate costs, and the cost of implementation will depend on the depth of the investment.

The cost of *not* implementing a National ASD Strategy, however, is much higher than investing in the supports that are needed. Insufficient supports push people with ASD and their family members out of the workforce and make them more likely to use other costly services, from emergency resources to mental health supports and social assistance.

Why a federal strategy? Isn't autism a provincial issue?

ASD is not just a provincial responsibility or a federal responsibility. It is a Canadian responsibility.

While many of the health, education and social services that support people with ASD fall under provincial jurisdiction, the federal government holds some very important levers within its own jurisdiction that can make a significant impact. As well, we believe federal leadership can support improvements to provincial and territorial government policies and programs across all regions.

As a national coalition, CASDA will continue to work with partners to support them to advocate for needed improvements at the provincial and territorial level.

Does the Blueprint recommend changes to the *Canada Health Act*?

CASDA recognizes that too many healthcare needs for people with ASD are not covered by provincial health systems. This is unacceptable and CASDA will continue to support partner organizations in advocating for expanded provincial healthcare coverage for people with ASD. Because the *Canada Health Act* is a broad piece of legislation that does not deal with the needs

of specific conditions such as ASD, the Blueprint does not focus on the *Canada Health Act* as a pathway to achieve this change.

Does CASDA’s Blueprint have recommendations on education?

Education (including post-secondary) is primarily the responsibility of provincial and territorial governments, and so it is not identified as a key focus area for the Blueprint.

The Blueprint does outline actions in the area of affordability and access that the federal government can take to make expenses associated with ASD, including childcare and education, more affordable for Canadians with ASD and their families.

What does the Blueprint have to say about mental health?

We know that an ASD diagnosis is often associated with co-occurring mental health conditions. The Blueprint advocates for increased mental health supports in federal health systems for people with ASD. The Blueprint also advocates for improved training of ASD professionals, building a learning network for practitioners and policymakers to gather evidence and consensus on necessary supports.

CASDA also recognizes that strong mental health requires access to appropriate services. For this reason, the Blueprint advocates for improved services in many areas, including employment and housing.

Does CASDA want to see the Ontario Autism Program be a model for the rest of Canada?

No. The recent actions by the Ontario government and the community’s advocacy in response have made clear what we already know: that people with ASD and their families need greater access to services and supports. People with ASD in Ontario do not have access to the supports and services they need.

The Blueprint calls on the federal government to create a platform for people with ASD, their families, practitioners, and provincial and territorial governments to share learning and knowledge to support the development of evidence-based and comprehensive service models across the country.

What does it mean to have a cross-government approach to ASD?

People with ASD and their families are impacted by services, supports and policies across governments. For example, the Department of Finance is responsible for designing the Disability Tax Credit, while the Department of Employment and Social Development is responsible for funding employment programs.

This work is all important, but it is not coordinated. Currently, the parts of government that provide services to people with ASD are not set up to learn from each other or design their programs and services to complement each other.

We are asking the Prime Minister to designate a lead minister for the National ASD Strategy, who would be responsible for ensuring all ministries and agencies are working together to implement the strategy. In the Blueprint, CASDA recommends that the lead minister be supported by a coordinating table of senior public servants from relevant ministries. It is essential that a cross-government approach also embed a deep and wide ongoing consultation with people with ASD and their families.

What's next?

CASDA's Blueprint identifies 5 areas of immediate federal action. Is there room to add onto these focus areas?

The Blueprint is meant to secure a commitment from the federal government to develop a full National ASD Strategy by providing a vision of what that strategy could look like.

However, CASDA wants the Blueprint to be the beginning of the discussion, not the end of it.

We expect the federal government to consult deeply and widely with the ASD community on the details of a National ASD Strategy. We see the Blueprint as a starting point for that plan.

We will advocate for the details of the National ASD Strategy to be developed in partnership with the ASD community.

What will CASDA's role will be in the National Strategy implementation?

CASDA intends to continue to be a driving force behind a National ASD Strategy. CASDA wants to ensure that there is deep, broad and meaningful consultation with the ASD community including people with ASD, their families and experts/service providers from across the country to validate and design the final strategy the government will implement.

Is CASDA also developing tools for advocacy around provincial ASD policies?

CASDA is dedicated to building the advocacy capacity of our member organizations. We held a session at our most recent Leadership Summit on best practices for effective advocacy, and we are looking at more ways to support organizations in their engagement with provincial and territorial governments.

The Blueprint calls on the federal government to facilitate better cooperation and coordination across provinces and territories. This could include developing a platform to allow clinicians, researchers, service providers, ASD self-advocates and provinces and territories to develop and share best approaches to a continuum of care for people with ASD. The Blueprint also suggests that federal and provincial governments have a multi-ministry intergovernmental meeting on ASD.

How can I contribute?

With an election this fall, we are asking all political parties to commit to a National Autism Strategy. You can add your voice with a [letter of support](#), and by letting your local candidates know we need a National Autism Strategy when they knock on your door or at events in your riding.

We want the Blueprint to be the beginning of a conversation on how to best influence change through a National ASD Strategy, not the final word. CASDA will continue to press the federal government to engage in meaningful consultations, and we will continue to reach into the expertise of our community to put forward recommendations that will improve the lives of Canadians with ASD.