

What Our Provinces and Territories Need From a National Autism Strategy: Continuing the Conversation

A product of the 2023 Annual Canadian Autism Leadership Summit

This brief is a product of Autism Alliance of Canada's 2023 Canadian Autism Leadership Summit ("Summit"). This document presents a snapshot of a panel presentation and group discussions about what Canadian provinces and territories need from a National Autism Strategy. Participants included Autistic advocates, caregivers, policymakers, community organization representatives, practitioners, and researchers.

What You Can Do with this Brief

As a Policymaker

This brief can provide important information about lessons learned from other provinces and territories. It can also show you what the community thinks is most important so you can focus on those things in your work.

As a Community Leader

Use it to start discussions in your community, gather opinions on how your region is doing, and bring awareness of current topics to your local government.

As a Researcher

This brief can give you ideas about what we still need to learn about different services and supports across Canada and what works and why. It might inspire you to explore new research topics.

As an Advocate

This brief can be a good starting point for talking to policymakers and other advocates about what is happening in and beyond your local area.

Current Landscape

Each province and territory in Canada is responsible for delivering services and supports to Autistic Canadians and their families. Since each jurisdiction is diverse, there are differences in how these services and supports are provided. A National Autism Strategy can create a more harmonized and evidence-informed approach across these jurisdictions to support Autistic people and their families across the nation.

Advancing the Conversation: What We Heard

Panel: What do our Provinces and Territories need from a National Autism Strategy?

Dr. Karen Bopp (Co-Chair, Autism Alliance of Canada's Board of Directors, Director, Autism Information Services BC and Director, Provincial Outreach, CIRCA, UBC) moderated this panel on what our provinces and territories need from a National Autism Strategy with presenters **Jennifer Covey** (Coordinator with the Department of Health and Wellness Government of Nova Scotia), **Lyndon Parakin** (Vice President, Autism Society Alberta), **Margaret Spoelstra** (Executive Director, Autism Ontario), **Carolyn Kamper** (Assistant Deputy Minister, Strategic Integration, Policy and Legislation Division, Government of British Columbia) and **Cynthia Carroll** (Executive Director, Autism Nova Scotia).

From the panelists

At the Summit, participants watched [a panel presentation](#) with experts on what our provinces and territories need from a National Autism Strategy to better address inclusion and service delivery barriers and general gaps in autism support across Canada. When asked what provinces and territories need from a federal autism strategy for improved social and political inclusion, two experts provided their input.

According to **Carolyn Kamper** and **Cynthia Carroll**, a National Autism Strategy should focus on the following areas to improve social and political inclusion:

- 1 Consistent and timely diagnostic assessments to reduce wait times and ensure equitable access**
- 2 Revision of the funding model to provide support based on individual needs**
- 3 Active engagement of stakeholders**

- 4** Collaboration among provinces and territories to establish an integrated system of support
- 5** Development of a comprehensive framework and national approach that brings together key players from all provinces and territories
- 6** Adequate funding for autism services and support, moving beyond tax credits and integrating various funding sources across multiple departments.

Panelists shared the following examples of success in autism programs and service delivery models across various provinces and territories:

ECHO Autism Psychology Program (Ontario)

This program provides training to psychologists and allied health professionals on diagnosing autism and managing interfering behaviors in school settings. The goal is to identify and assess children earlier and facilitate their placement into appropriate programs.

Independent Intake Organization (Ontario)

This organization streamlines the process of accessing services within the Ontario Autism Program (OAP) by providing a centralized resource hub for families.

Children's Mental Health Ontario (CMHO) (Ontario)

CMHO offers a free training program for autism and mental health providers to enhance their expertise in supporting children, youth, and families.

Province of Ontario Neurodevelopmental Network (POND) (Ontario)

POND is a research network focused on understanding the biology of neurodevelopmental disorders, including autism, to inform effective treatments.

Collaborative Approaches (Alberta)

Successful autism programs and service delivery models emphasize collaboration among stakeholders. Autism Society Alberta highlights the importance of setting aside differences and finding common ground by learning from national successes.

Early Intensive Behavioral Intervention (EIBI) Program (Nova Scotia)

This program supports the social-communication skills development of preschool children with autism. Nova Scotia faced challenges with funding and limited service options, but initiatives such as pilot programs, increased diagnostic assessments, and implementing the ECHO model have been undertaken to address these issues.

QuickStart Nova Scotia (Nova Scotia)

QuickStart is a parent-mediated coaching program that assists parents and caregivers of toddlers with autism in supporting their child's development. It is open to anyone in Nova Scotia.

Experts described what information or steps were lacking for a National Autism Strategy in their regions. They discussed the importance of an **aligned framework involving key players from all provinces and territories** at the national level by reflecting on successful models emphasizing **effective coordination and cooperation**. Collaboration and coordination were discussed in terms of their importance for a **cohesive** national strategy and also at the level of cross-ministerial collaboration and the **effective integration** between research and health services.

Experts discussed urgent action required to **reduce wait times for diagnosis and access to services** while considering the aging Autistic population. Panelists highlighted **inadequate funding support and services** for Autistic adults and emphasized taking a lifespan approach.

Experts described funding inequities, especially around housing and support services, that need to be addressed at the federal level. The panelists highlighted how essential it is to **integrate human rights principles into the decision-making steps** at both provincial and national levels.

From our members

Following the panel presentation, Summit attendees participated in **group discussions** to reflect on two guiding questions. The first question was, “*If you had a chance to add something to the Federal/Provincial/Territorial meeting agenda, what topic(s) would you add?*” The second question was, “*What actions do you want the federal, provincial, and territorial governments to commit to?*” They recorded their answers on sticky notes¹, which were collected. After the Summit, similar sticky note answers were grouped.

Boxes 1 and 2 show the types of responses Summit attendees wrote about. Attendees provided feedback on what they wanted to be added to the provincial-territorial meeting agenda if given the opportunity (*Box 1*). Also, Summit attendees highlighted the actions they wanted the federal, provincial, and territorial governments to commit to that they felt would make the most significant impact with the least effort (*Box 2*).

¹ Online attendees recorded their answers on virtual sticky notes using *Jamboard*.

Box 1. Topics attendees would add to the provincial-territorial meeting agenda

- Funding/money for Autistic people
- Providing youth and adult services
- Education for Autistic youth and adults
- Conducting research and collecting data
- Work on a National Autism Strategy
- Supporting needs and providing youth and adult supports
- Helping Autistics with work, career, employment
- Supporting Autistic people/those with lived experience
- Housing for Autistic adults
- Engagement with government, ministries, and other sectors
- Solving waitlist and assessment issues
- Involving and working with Indigenous peoples

Examples of comments related to “Funding/money for Autistic individuals”

“Federal funding and direction that supports more consistent and equitable provision of services across provinces and territories.”

“One stop funding for Autistic adults.”

“Clear pathway for service delivery in province (how will money flow so that services will activate quickly and effectively).”

Examples of comments related to “Providing youth and adult services”

“Connect children's services to young adults and adults for seamless services.”

“Workforce capacity strategies to deliver services across the lifespan.”

“Equitable access to early diagnosis and one-stop shop access to early intervention”



Box 2. Categories of “high impact, low effort” actions participants want the federal, provincial, territorial government to commit to

- Funding
- “Nothing About Us Without Us”
- Authentic engagement
- Communication, collaboration
- Address barriers to accessing services or resources
- Training and education for professionals
- Research
- Bill C-22
- Surveillance
- Human rights lens
- Job strategy
- Reciprocity

Examples of comments that related to “Funding”

“Individualized funding for Autistic adults”

“Clear process for funding flow to service providers.”

“Multi-year funding to support community organizations to deliver mental health services to Autistic adults”

Examples of comments that related to “Nothing About Us Without Us” and “Authentic engagement”

“Listen to those that know (lived experiences).”

“Targeted engagement of Autistic civil servants in policy development, service design and delivery of National Autism Strategy (nothing about us without us).”

“Authentic listening and action based on lived experiences informed research”



Next Steps: What We Will Do at the Alliance

Call to action: Autism Alliance of Canada recommends several actionable steps to support provincial and territorial work toward a National Autism Strategy. **We are calling for provincial and territorial action plans that align with the federal National Autism Strategy.** We will convene a provincial-territorial policy forum to provide an opportunity for key players to learn and share information across jurisdictions with the aim of continuous improvement and feedback.

At our **2024 Canadian Autism Leadership Summit**, we will invite regional (provincial, territorial, Indigenous) government representatives to discuss progress on aligning regional action plans under a federal strategy, frameworks that work across ministries in regional governments, and identifying implementation gaps and issues.

To learn more about CALS2024, visit: autismalliance.ca/cals/cals/cals2024



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