Community Brief

Unpacking Priority Area #1 of Canada’s Autism Strategy - Screening, Diagnosis & Services

What we heard from the 11th annual Canadian Autism Leadership Summit participants.

This brief was created following Autism Alliance of Canada's 11th annual Canadian Autism Leadership Summit. It summarizes key ideas and reflections shared by attendees during World Café discussions after a panel presentation on *Screening, Diagnosis, and Services*.

How you can use this brief

As a Policymaker

This brief offers valuable community perspectives on screening, diagnosis and services. Whether you’re working at the federal or provincial level, these insights can help inform policies and programs that support a more effective and coordinated approach to autism support across Canada.

As a Researcher

This brief highlights gaps and community-identified needs related to screening, diagnosis and services. It can help spark new research questions and guide studies that support meaningful real-world improvements.

As a Community Leader

This brief can help spark local conversations and provide context for national efforts on screening, diagnosis and services - so you can bring your community’s experiences and connections into the national conversation.

As an Advocate

This brief can support your efforts to engage with policymakers and fellow advocates in your region. It offers a starting point for conversations about building a more coordinated national approach to screening, diagnosis and services.

Autism Alliance of Canada | Alliance canadienne de l’autisme

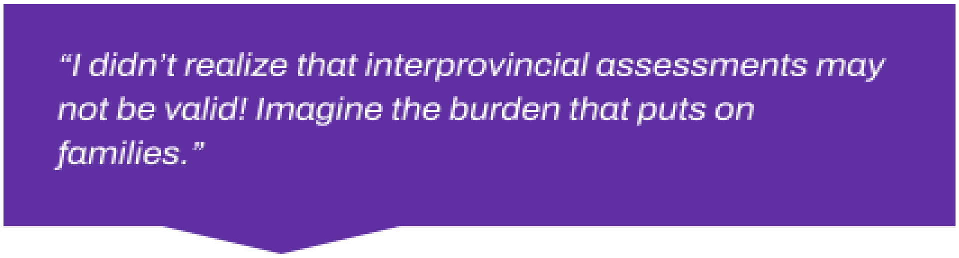
Panel and World Café Engagement

Panelists explored bold actions the government could take to improve access to autism screening and services, identified key challenges and opportunities across the lifespan, and shared their vision of what success could look like. Following the panel, attendees reflected on these ideas during World Cafe discussions and contributed their own perspectives. Key themes from those conversations are summarized below along with quotes that capture the spirit of the dialogue.

Panelists: Dr. Ghita Wiebe, Dr. Amanda Evans, Jessie Gartshore, Siyu (Suzanna) Chen, Dr. Caroline Roncadin

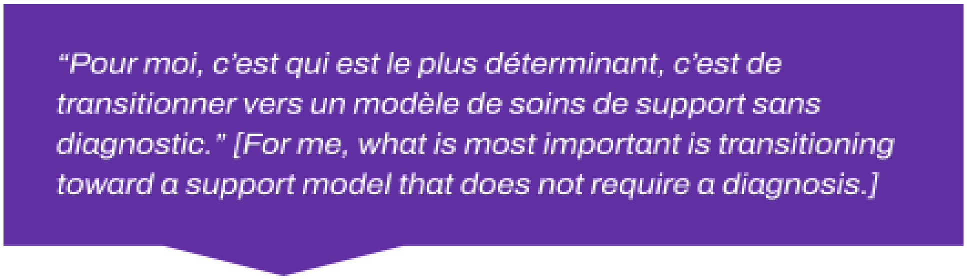
What we heard: reflections from attendees

1. **Diagnosis varies across provinces - and it's hurting families.** Autism diagnoses are not recognized consistently across provinces and territories, leading to disruption, financial strain, and emotional stress for families who relocate.



"I didn't realize that interprovincial assessments may not be valid! Imagine the burden that puts on families."

2. **A call for needs-based, not diagnosis-based, support.** Many emphasized the harm of requiring a formal diagnosis to access services and argued for models that support people based on actual needs instead.



"Pour moi, c'est qui est le plus déterminant, c'est de transitionner vers un modèle de soins de support sans diagnostic." [For me, what is most important is transitioning toward a support model that does not require a diagnosis.]

3. **Diagnostic tools reflect norms that exclude.** Attendees expressed concern about standardized diagnostic tools that fail to account for diverse neurodevelopmental presentations, especially among racialized and marginalized groups.
4. **The system lacks flexibility and leadership.** Participants described the current diagnostic process as rigid and outdated, often failing to reflect lived realities or neurodivergent identities.

> *"Understanding how neuro- normative standards embedded into assessments can block access to meaningful supports really stood out to me."*

***Box 1.* Supporting Evidence from the Canadian Academy of Health Sciences (CAHS) Autism Report, from *Equitable Access to Diagnosis, Supports, and Services* (p. 146)**

"Supports and services that are responsive to the needs of Autistic people offer programs that build on developmental growth and meet emerging challenges at different life stages, including through adulthood."

5. **Need for Culturally Safe, Accessible Services.** There was broad recognition of the cultural and systemic barriers faced by newcomers, racialized communities, and Indigenous peoples. Participants emphasized the need for more culturally affirming, trust-based approaches to care.
6. **The system is fragmented and lacks leadership.** There is a lack of coordination between governments, departments, and service sectors. More national leadership, transparency, and interprovincial sharing of successful programs are possible solutions.

Taking action on this priority

Attendees shared clear steps that policymakers, service providers, researchers, and community leaders can take.

1. **Standardize autism diagnosis across provinces.** Launch a federal-provincial working group to improve diagnostic processes across jurisdictions.
2. **Allow service access without a formal diagnosis.** Pilot needs-based funding in select regions for families awaiting diagnosis, removing diagnosis as a prerequisite for basic or early supports.

3. **Expand training in early identification and neuro-affirming care.** Introduce equity-focused learning modules for educators, physicians, and early care providers through professional networks.
4. **Implement community-based digital screening pilots.** Partner with regional health and early childhood service providers to develop screening tools targeting underserved communities.
5. **Map and share diagnostic pathways across regions.** Build a digital platform summarizing provincial and territorial autism diagnostic pathways to compare, identify, and target service gaps.
6. **Foster cross-sector collaboration (Health, Education, Justice).** Convene a national roundtable to align efforts in autism awareness, identification, and diagnostic referral practices across sectors.
7. **Enhance service navigation and reduce bureaucracy.** Deploy navigators in pilot sites to help families understand available supports and services, and reduce barriers to access.

Gaps that need attention

During the discussions, participants raised important issues that are often overlooked in policy and practice. By highlighting these gaps, we can include a broader range of voices and better address the diverse needs of our community.

1. **Adult diagnosis and post-diagnostic supports are largely ignored,** especially for older adults and those diagnosed late in life. Stigma for adults also remains an unaddressed barrier.
2. **Access to assessment and services is inequitable,** hindered by financial, geographic, and professional resource gaps - especially in remote areas, and for mobile families such as those with the military or RCMP.

***Box 2.* Supporting Evidence from the CAHS Autism Report, from *Recognition and Diagnosis Across the Lifespan* (p. 154)**

"Efficient and timely access to diagnostic services starts with early recognition of autism characteristics and other co-occurring conditions in multiple settings and by multiple partners, for example, families, educators, and health professionals."

> *"Pathways often favour families who are well-resourced, English-speaking, and urban-based, leaving marginalized communities behind."*

3. **Intersectionality needs greater attention in many current service contexts,** where gender, cultural, linguistic, and trauma-informed perspectives remain underrepresented.
4. **Too little attention is given to the education system as a key gateway for diagnosis and services,** particularly within the critical K-12 sector, which often excludes non-traditional profiles.
5. **Service access is tied too rigidly to formal diagnosis,** limiting supports for self-identified or undiagnosed Autistic people.
6. **More culturally responsive tools,** a greater disability justice orientation, and reforms to colonial diagnostic models are needed.

> *"How behaviours associated with autism can be overlooked or confused with other personal characteristics (e.g., the student is quiet because they're an immigrant)."*

7. **Families need more inclusive system navigation support** to be able to access services equitably, including multilingual translation and resources adapted for specific groups.

***Box 3.* Supporting Evidence from the CAHS Autism Report, from *Equitable Access to Diagnosis, Supports, and Services* (p. 146)**

"Improving systems design and coordination and providing family-centred navigation supports ensures greater access to and continuity of services for Autistic people across the lifespan."

The National Autism Network: Engaging Community for Impact

Attendees shared ideas on how Canada's new Autism Network can meaningfully involve autistic people, families, and communities to advance this priority through trust, collaboration, and shared action.

Box 4. **Supporting Evidence from the CAHS Autism Report, from *Equitable Access to Diagnosis, Supports, and Services* (p. 146)**

"Remote technologies, such as tele- and e-health, as well as mobile developmental clinics, and university-service partnerships, offer Autistic people and their families more effective access and opportunities to participate in some assessments and interventions that may otherwise be unavailable, for example, in rural, remote, and northern areas of Canada."

1. **Launch a *National Listening Tour*** by hosting town halls, community dialogues, and storytelling sessions prioritizing underserved groups (e.g., Indigenous, newcomer, rural, and racialized families).

> *"Please do not forget about intersectionality!"*

2. **Continue developing *Lived Experience Advisory Councils*** (including Autistic people and caregivers) to provide input on screening and diagnostic policies.
3. **Co-create community-led models** such as mobile outreach clinics, especially to serve equity-deserving and newcomer populations.
4. **Develop a national digital collaboration hub** for families, clinicians, researchers, and policy makers to co-design tools, track service access, and share best practices.
5. **Coordinate culturally rooted service design** by co-creating diagnostic pathways with Indigenous and ethnocultural communities, respecting local knowledge systems.

> *"Listen and learn from First Nations, Inuit ,and Métis communities, which have a foundation of neuro-affirming approaches and celebrate people for who they are."*

6. **Champion national standards for portable diagnostic recognition** to ensure continuity of care when people move across provinces.
7. **Host innovation challenges** (e.g., AI screening tools, culturally adapted assessments) to spur community-driven solutions.
8. **Ensure francophone inclusion** by organizing French-language forums and resources for Francophone Autistic people and families.

Acknowledgements

We are deeply grateful to all the Summit attendees who generously shared their time, experiences, and insights. Your contributions are at the heart of our work and continue to shape the path toward more inclusive and responsive autism policies in Canada.

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