

# International Learnings for a National Autism Strategy

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”). It contains information about the event, what we talked about there, and what comes next for the Alliance based on the event. Here, we talk about how we're learning from other countries to create a National Autism Strategy in Canada. 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 you with important information about lessons learned from other countries that have implemented autism strategies. It can also show you what the community thinks is most important, so you can focus on those things in your work.

### As a Researcher

This brief can give you ideas about what we still need to learn about autism strategies worldwide. It might inspire you to explore new research topics.

### As a Community Leader

You can use this brief to start discussions in your community and get people's opinions on the National Autism Strategy.

### As an Advocate

This brief can be a starting point for talking to policymakers and other advocates about Canada's National Autism Strategy.

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## Current Landscape

Governments around the world have different ways of making policies and strategies to help Autistic people. They do this based on politics, culture, and other factors. Also, not all countries are at the same point in making these policies, and they might not follow the [United Nations Convention on the Rights of Persons with Disabilities \(CRPD\)](#) in the same way. By learning from each other, policymakers from different countries can make their policies and strategies better. This will make life better for Autistic people and their families everywhere.

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## Advancing the Conversation: What We Heard

### From the panelists

At the Summit, people watched two panels with experts talking about autism policies in different countries. One panel looked at [autism around the world](#), and the other talked about [how these policies help Autistic people](#).

The panelists talked about how, in their countries, the strategies ensure that **Autistic people are genuinely involved in decision-making**, especially by listening to and prioritizing their opinions and perspectives. In the United States, Dr. Susan Daniels shared an example of prioritizing Autistic people and their families' voices: *"We originally had the Combating Autism Act of 2006 to ensure that there would be public input into the federal policymaking effort for autism, and [to ensure] it includes Autistic individuals and family members as a part of that law."*

Panelists also discussed **intersectionality and equitable care**. Dr. Daniels stated that *"[practitioners focus on] new and improved screening and diagnostic tools for a reduction in disparities in identification of autism across various communities."*

Lastly, there was a lot of talk about the importance of national autism strategies taking a **life-course approach** by considering the **whole life journey of people on the autism spectrum**. Dr. de Gaetano, drawing from his experience in Malta, highlighted this lifespan perspective: *"It is a lifelong strategy. So we don't just look at children, we also look at life course and also practical measures that are required for when these*

*children actually grow up.” Harald Neerland took this point a step further, stating that “one of [the policymakers’] mantras is a rights-based approach to autism via legislation.” and that “These initiatives have to look at access to diagnosis, access to education, access to healthcare, access to services, access to employment, and, last but not least, access to justice.”*

## **From our members**

Following the panel presentations, members participated in group discussions to reflect on what was most important to them when thinking about the development of a Canadian National Autism Strategy. Members split into groups to talk about and share what they thought was really important when developing an autism strategy on a national level. *Box 1*, shows the most important things that got the attention of Summit attendees about how other countries developed their national autism strategies. A major point was how crucial it is to have a **variety of Autistic people involved and actively taking part in creating the plan.**

The examples below highlight the importance of having different Autistic voices included.

**Here are some examples of what people said when asked, “What’s the most powerful idea you heard this morning, and why?”**

“We need to involve Autistic people in the plans and policies that affect them.”

“Importance of amplifying voices of people with lived experience and ensuring they are valued and safe to tell their story”

“Nothing about us without us.”

Members also emphasized how crucial it is to think about autism policies throughout a person's life.

**Here are examples of what some people said about this:**

“Developing a strategy that focuses across a life course. It isn’t just about the childhood years.”

“Lifelong strategies. Neuro-affirming care, not just deficits”



## Box 1. Elements of national autism strategies from other countries that were most salient to Summit participants

- Diverse Autistic representation and involvement
- Inter-governmental and cross-disciplinary collaboration
- Accessible and barrier-free services
- Intersectionality
- Funding for research and more comprehensive data
- Accountability within policies
- Individualized approach to supports and services
- Education, training and guidance for Autistic people or general population
- Continual monitoring, evaluation, and adaptation
- Funding
- Strengths-based approaches
- Lifespan care
- Indigenous communities

Participants did not just talk about what they liked about other countries' strategies; they also shared what they believed should be part of a National Autism Strategy. These ideas are listed in *Box 2*. Once more, the point of **having a diverse representation of Autistic people** was important to members. Appropriate community representation is crucial when creating a National Autism Strategy.

**Here are some answers from participants when they were asked, "If success was guaranteed, from what you've heard so far, what would you want Canada to adopt in our National Autism Strategy?"**

"Having media initiatives that represent autism in an accurate way."

"Develop an Autistic committee for all government planning groups"

"Hire Autistic people to positions of decision makers for all school boards, municipal government, provincial and federal government."

Additionally, participants talked about making sure services and help for the Autistic community are easy to get.



**Here are examples of what some people said about this:**

“Simplification of government forms”

“Accessible pathways into and through post-secondary education with neuro-affirming support”

“Improved accessibility to services/resources for families, academic institutions, social centres, healthcare, and mental health facilities (employment, housing education, justice/law enforcement) across communities.”

Participants also described other important ideas when thinking about what should be included in a Canadian autism strategy. Here they are:

**Box 2. What Summit participants said they would want Canada to adopt in its National Autism Strategy**

- Accessibility to services and supports
- Autistic representation and diversity
- Education and training for the general population and care providers
- Inter-governmental and cross-disciplinary collaboration
- Funding and finances
- Intersectionality
- Educational supports for people on the spectrum
- Holistic and individualized approach
- Continual monitoring and evaluation
- Lifespan care
- Comprehensive data collection
- Indigenous-specific parallel strategy

## Next Steps: What We Will Do at the Alliance

### 1 International Autism Policy Working Group

Autism Alliance of Canada is starting a group called the International Autism Policy Working Group, which aims to help Autistic people around the world by sharing information and coming up with ideas for better policies. In this group, we want to share what works in different countries, so everyone can learn from each other and make their own autism strategies and policies better. This group will let us share the best ways to help Autistic people and use strategies that really work. These talks will also help us in Canada as we work on developing and implementing our National Autism Strategy.

**Working Group Mission:** *We want to push for fair policies that help and empower Autistic people and their families, so they can take part fully in society.*





## **2** 2024 Annual Canadian Autism Leadership Summit

In addition to launching our International Autism Policy Working Group described above, in 2024, at our next Summit, we will bring together our members to continue to gather valuable insights from other nations regarding the development of a National Autism Strategy in Canada. This means that we want to continue to learn from the experiences and approaches of other countries and discuss them to help inform our own strategy for supporting Autistic people and their loved ones in Canada. This collaborative effort will help us make more informed decisions and design a strategy that is well-informed, effective, and inclusive in Canada.

*To learn more about CALS2024, we invite you to visit:*

[autismalliance.ca/cals/cals/cals2024](https://autismalliance.ca/cals/cals/cals2024)

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