

Project Snapshot

Assessing the Value of a Future National Autism Research Network in Canada

December 2024

Autism Alliance of Canada is committed to supporting the implementation of Canada’s Autism Strategy. One of the actions that may arise from the strategy is the creation of a national autism research network. The aim of the network would be to increase collaboration in Canada’s research ecosystem and advance research to improve the health and well-being of Autistic people and their caregivers. Through an exploratory survey, the Alliance gathered insights from both the autism community and the research sector to guide the development of this future network. Survey respondents agreed that the network should unite existing efforts, promote inclusive research, and ensure the integration of knowledge into policy and practice.



1 What we did

The research team at Autism Alliance of Canada developed a survey with two separate streams. One hundred and twelve responses were collected during March and April 2024, representing most Canadian provinces.

Research survey



39 academics, researchers and research students/trainees

Community survey



73 people with lived experience of autism or disability in general, family members, services providers, health professionals, and employees at community organizations

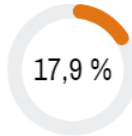
Main identity of the participants:



Autistic or Neurodivergent



Researcher/Scientist



Family member/Support person

2

What we found

The autism community and researchers largely **agree on the most important research areas that should be covered in the network.**



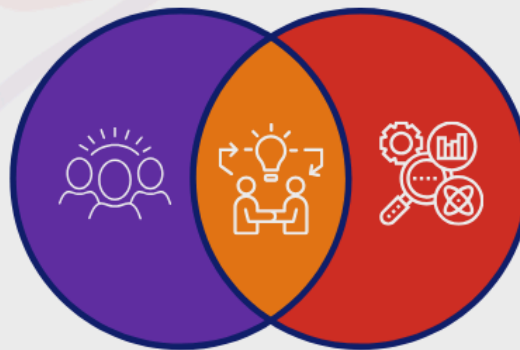
FUTURE AUTISM RESEARCH NETWORK PRIORITY AREAS

Based on a survey run by Autism Alliance of Canada, different research priorities were identified for a future autism research network by community members and researchers.



COMMUNITY SURVEY (C)

Intersectionality (26%)
Aging/Adulthood (21%)
Employment (21%)
Autism Diagnosis (14%)
Co-occurring Conditions (5%)



RESEARCHER SURVEY (R)

Clinical Systems (26%)
Knowledge Translation (21%)



SHARED PRIORITIES

Support systems
 (28% C, 41% R)
Social Science
 (15% C, 36% R)
Mental Health
 (16% C, 10% R)
Education
 (16% C, 5% R)
Participatory Research
 (11% C, 15% R)



The current functioning of public & private healthcare system that autistic people have to utilize for diagnostic services & support/referral needs to be reviewed at a national level for all age groups. In my local city, I faced significant barriers to receiving my diagnosis & supports, and I fear that many undiagnosed & diagnosed people are falling through the cracks of the system.

Autistic person, Alberta



More focus on autistic led, diverse, community engaged approaches, and collaboration with family, kin, and educators and practitioners who wish to change systems.

Researcher, Ontario

Read the full report

<http://autismalliance.ca/Research-Network-Report>

Bringing Value: What do members hope to gain from joining a national research network?

Community Responses



1

Participate in setting research priorities that reflect community needs

2

Influence how policies are made

3

Work together with research teams on projects

Researcher Responses



1

The opportunity to collaborate on interdisciplinary research projects and grants

2

Engagement with persons with lived experience and access to diverse perspectives

3

Access to funding opportunities

Key Events and Activities: What events or activities would members like to have in the network?

Community Responses



1

Deciding on important research questions

2

Online presentations

3

Training sessions and workshops to learn new skills

Researcher Responses



1

In-person annual conference on autism research in Canada

2

Priority setting exercises to identify priority research questions consistent with the community's needs

3

Working on a pan-Canadian grant with other researchers

“Unifying the disability community by advocating & pushing for policies and systems [is what] will end up benefiting all those with disabilities.”

Autistic or Neurodivergent person, Alberta

Where do we go from here?

This report highlights the autism and research community's shared vision for an inclusive and participatory national autism research network focused on lived experience. By amplifying the voices of Autistic people and fostering collaboration, accessibility and innovation, this network could transform research, inform policy and address the real needs of Autistic people.

Its establishment will require discussions on its scope, priorities, strategic alignment and practical organization, including leadership, funding and governance. The support of the federal government is crucial to ensure a strong and sustainable network, capable of concretely improving the lives of Autistic people by integrating their needs into research and policy.

By building on the solid foundation of work already underway, and by focusing on the voices of people with lived experience, this network can lead to significant progress that will drive forward the goals of Canada's Autism Strategy.



Autism
Alliance of Canada

Alliance canadienne de
l'autisme

Read the Full Report:

www.autismalliance.ca/Research-Network-Report

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