



Autism
Alliance of Canada

Alliance canadienne de
l'autisme

Evidence that Matters: Research to Support Autistic People

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What are we going to talk about today:

1. Who we are and the organizations we are representing today
2. The power of using evidence to battle misinformation
3. What is good evidence
4. What is happening at the national level to center autistic people and their families in research and policy making

Funding and Positionality

Primary sources of Funding:

- Canadian Institutes of Health Research Health System Impact Early Career Award
- Ron Joyce Foundation and Hamilton Health Sciences Foundation
- Sinneave Family Foundation
- Public Health Agency of Canada

Roles:

- Karen: Ceo of the National Autism Network
- Deepa: Scientific Director, Autism Alliance of Canada
 - Adjunct Assistant Professor, Department of Pediatrics, University of Alberta
 - Mom of a neurodivergent and neurotypical child

Who we are

Autism Alliance of Canada is a pan-Canadian network with a broad and diverse membership of Autistic people and their families and support persons, as well as clinicians, researchers, policy influencers, service providers and organizations from across Canada.



Vision and Mission

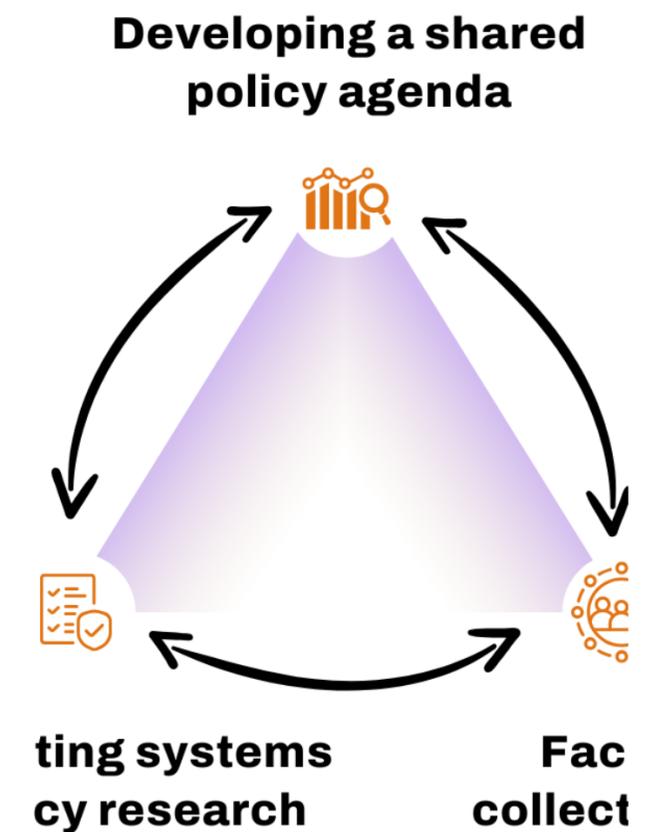
Our vision is a Canada where Autistic people exercise their full rights and realize their full potential.

Our mission to inform policy and practice at a national level by bringing our members together, identifying priority issues, and developing meaningful ways to address them.



Our Goal: A Bridge and a Platform

1. Convener to bring together families, clinicians, researchers, community organizations and the federal government
2. Resource to bring community voices into national policy
3. Create accessible evidence and research
4. Ensure Autistic people and families at the center for shaping research that may inform policy



The National Autism Network



Mission:

- Driven by Autistic people and their Families the Network informs Canada's National Autism Strategy and helps share a future where Autistic people thrive

Vision

- A Canada where the lived and living experiences of Autistic People and their families shape policies, systems, and communities to foster full inclusion, equity, and opportunity at every stage



Why this talk now – Information overload

Average person is exposed to **30 to 40 gigabytes of information daily**, coming from news media, social media, messaging apps, podcasts, AI-generated content, and online communities.

Why evidence matters right now

- Autism misinformation is widespread
- Evidence shapes whose voices are believed
- Misinformation causes great harm

When evidence becomes public responsibility



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**Affirming
Evidence, Dignity,
and Inclusion in
Autism Discourse**

Myths to Combat with Evidence

1. Autism is an epidemic
2. Prenatal Tylenol use causes Autism
3. Leucovorin is a “cure” for autism

Responding with Evidence

What we released

- Evidence informed public statement
- Clear correction of false claims

Take home messages:

1. Rise in autism rates are not a crisis
2. Prenatal Tylenol does not cause autism
3. Leucovorin is not a cure for autism



**Addressing Rising
Autism Prevalence
with Scientific
Integrity and Insight**

Bring back the focus: Reaffirm our national priorities for action

“Health Canada currently maintains that there is no conclusive evidence that using acetaminophen as directed during pregnancy causes autism or other neurodevelopmental disorders.

Acetaminophen is commonly used to relieve pain and reduce fever. It has been used safely by millions of Canadians for decades, including during pregnancy and while breastfeeding.

Acetaminophen is a recommended treatment of pain or fever in pregnancy when used as directed. It should be used at the lowest effective dose for the shortest duration needed. Untreated fever and pain in pregnant women can pose risks to the unborn child”

- Health Canada statement, September 9, 2025

Rising Autism Prevalence – Responsibility not crisis

- **Global: 1 to 2 percent of children worldwide** are autistic
(approximately **10 to 20 out of every 1,000 children**)
- **United States: In 2022**, an estimated **1 in 31 children** met diagnostic criteria
(**32.2 per 1,000 8-year-olds**)
 - This increase from **1 in 36 children (27.6 per 1,000)**

Source: Autism and Developmental Disabilities Monitoring (ADDMM) Network
- **Canada: National prevalence estimates for children and youth increased from:**
1 in 714 children (0.14 percent) in 2000–2001
to
1 in 44 children (2.25 percent) in 2023–2024

Source: Public Health Agency of Canada, 2025

What does this mean? The System is better at seeing people who were always here

Rising prevalence most likely reflects:

- Broader diagnostic criteria
- Improved identification and screening
- Improved understanding of autism
 - Inclusion of historically overlooked groups – females, LGBTQ, rural and remote
- Better data and management systems

Take home message: Our education, health, and social systems must be prepared to **support and include autistic people across the lifespan**

Behind every number there is a person

[Home](#) > [Canadian Journal of Public Health](#) > [Article](#)

Prevalence and incidence of autism in children and adolescents in Manitoba, Canada: An updated estimate using population-based administrative health data from 2011 to 2022

Original Article | [Open access](#) | Published: 16 October 2025

(2025) [Cite this article](#)

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What we found:

- **Autism prevalence increased from 0.58% in 2011 to 1.67% in 2022**
- **Used this information to advocate for supports and system change in Manitoba**

Expertise Today – Who is the expert ?

Who is an expert anymore?

- Information is everywhere
- Not all sources are credible
- Process matters more than confidence

What to look for:

- Who is funding them?
- Who is supporting them?
- What is their positionality?
- What is their track record?
- Do they recognize their scope of knowledge?

Case Example: Why should you trust this report?

Source
Methodology
Expert review
Transparent limitations
Clear distinction between evidence and uncertainty

Evidence Summary in Everyday Language

Leucovorin (Folinic Acid) and Autism:
What We Know So Far

November 2025

How to Evaluate A Research Claim

A few key messages:

- Who is the source?
- Sample size and representativeness
- One study vs. a body of evidence
- External validation
- Correlation is not causation

Correlation is not causation

What correlation means

- Two things occur together
- It does **not** explain why

• A familiar example:

- Crime rates rise in the summer
 - Ice cream sales also rise
 - Ice cream does **not** cause crime
 - A third factor (warm weather) influences both
-
- We must take into the effect of confounding factors

Applying this to autism research

- Some exposures and autism diagnoses occur together
- This shows **association**, not cause
- Many factors must be ruled out before causation can be claimed

Why this matters:

- Misinterpreting correlation can fuel fear and misinformation
- Causation requires rigorous, replicated evidence

Poor Evidence causes harm

- Over generalization
- False certainty
- Misguided decisions
- Stigma and harm
- Fear based policies rather than investments in support and inclusion

Does the research support autistic people or risks harming them?

Accessing Evidence without being a researcher

- Evidence syntheses and clinical or practice guidelines
- Plain-language summaries of systematic reviews that summarize evidence
- Knowledge translation products from trusted institutions
- **Prioritize sources that document methods, limitations, and lived-experience input**

Where to look: Credible Sources of Information

- Canadian Paediatric Society
- Public Health Agency of Canada
- Canadian Institutes of Health Research (Integrated Knowledge Translation)
- McMaster Health Forum
- SPOR Evidence Alliance
- Autism Alliance of Canada
- AIDE Canada
- Cochrane Collaboration
- Campbell Collaboration
- NICE Autism Guidelines
- Autism CRC (Australia)

Using your experience to shape research

- Top Ten Autism Research Priorities for Canada – NEW !
 - Aligned with Canadas National Autism Strategy
 - Building on the work done by Dr. Evdokia Anagnostou
- Lived Advisory Groups- to be launched next month

National Context

- Canada's National Autism Strategy
- National Autism Network
- Participation improves relevance



INFORM

the development of an implementation plan for Canada's Autism Strategy in collaboration with the Public Health Agency of Canada.



ENSURE

that ongoing community feedback and engagement are central to developing solutions that are informed by both experience and evidence.



SUPPORT

ongoing engagement with the Community, Standing Advisory Councils, and Strategic Priority Committees to inform the development of practical and actionable activities for each of the five priority areas in Canada's Autism Strategy, ensuring that all proposed actions lead to real, measurable, and meaningful change at the community level.



Canada's Autism Strategy Priority Areas

1. Screening, Diagnosis and Services
2. Economic Inclusion
3. Data Collection, Public Health Surveillance and Research
4. Public Awareness, Understanding and Acceptance
5. Tools and Resources

COMMUNITY ENGAGEMENT

INCLUDES: Engagement with Autism Community: In-Person; Virtual; Survey; etc.

PURPOSE: Strive to ensure that diverse perspectives from across the country are included, and that the information gathered will guide priority setting so that action plans make a real difference in peoples' lives.

FIVE STRATEGIC PRIORITY COMMITTEES

INCLUDES: Engagement with experts in systems, policy, research, and service, as well as experts with relevant lived and living experience across each of the five priority areas.

PURPOSE: Identify sustainable, effective, and evidence-informed actions that can improve policies and services, leading to meaningful and positive outcomes for Autistic people and their families in each priority area.

THREE STANDING ADVISORY COUNCILS

INCLUDES: Engagement through three Standing Councils: Autistic-led; Family/Caregiver-led; and Indigenous-led with each having a diverse range of lived and living experience.

PURPOSE: Reviews all five strategic priority areas and sets priorities to ensure that initiatives are more empathetic, effective, and grounded in real-world understanding.

ACTION PLANS

Propose practical and actionable ideas, opportunities, and solutions that will advance the implementation plan for the Framework for Autism in Canada and the actions in Canada's Autism Strategy. This includes providing input into policies and programs that support Autistic people and their families across the life course and focusing on clear goals and ways to measure progress.

Purpose



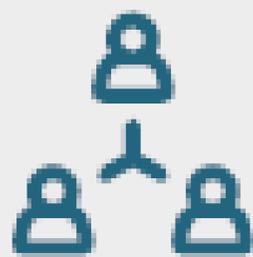
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Engagement Circle



Action Plans

Propose practical and actionable ideas, opportunities, and solutions that will advance the implementation plan for the actions in Canada's Autism Strategy. Providing input into policies and programs that support Autistic people and their families across the life course and focusing on clear goals and ways to measure progress.

Strategic Priority Committees

1. Screening, Diagnosis and Services
2. Economic Inclusion
3. Data Collection, Public Health Surveillance and Research
4. Public Awareness, Understanding and Acceptance
5. Tools and Resources

Engagement with experts in systems, policy, research, and service, as well as experts with relevant lived and living experience across each of the five priority areas

Engagement Circle



Standing Advisory Councils

Reviews all five strategic priority areas and sets priorities to ensure that initiatives are more empathetic, effective, and grounded in real-world understanding

Standing Advisory Councils

- Autistic Advisory Council
- Family Advisory Council
- Indigenous Advisory Council

Essential advisory bodies that anchor the Network's work in lived and living experience and ensure that the insights, priorities, and realities of Autistic people, families/caregivers, and Indigenous communities directly inform the activities that support the implementation of Canada's Autism Strategy

Engagement Circle



Community Engagement

Strive to ensure that diverse perspectives from across the country are included, and that the information gathered will guide priority setting so that action plans make a real difference in peoples' lives

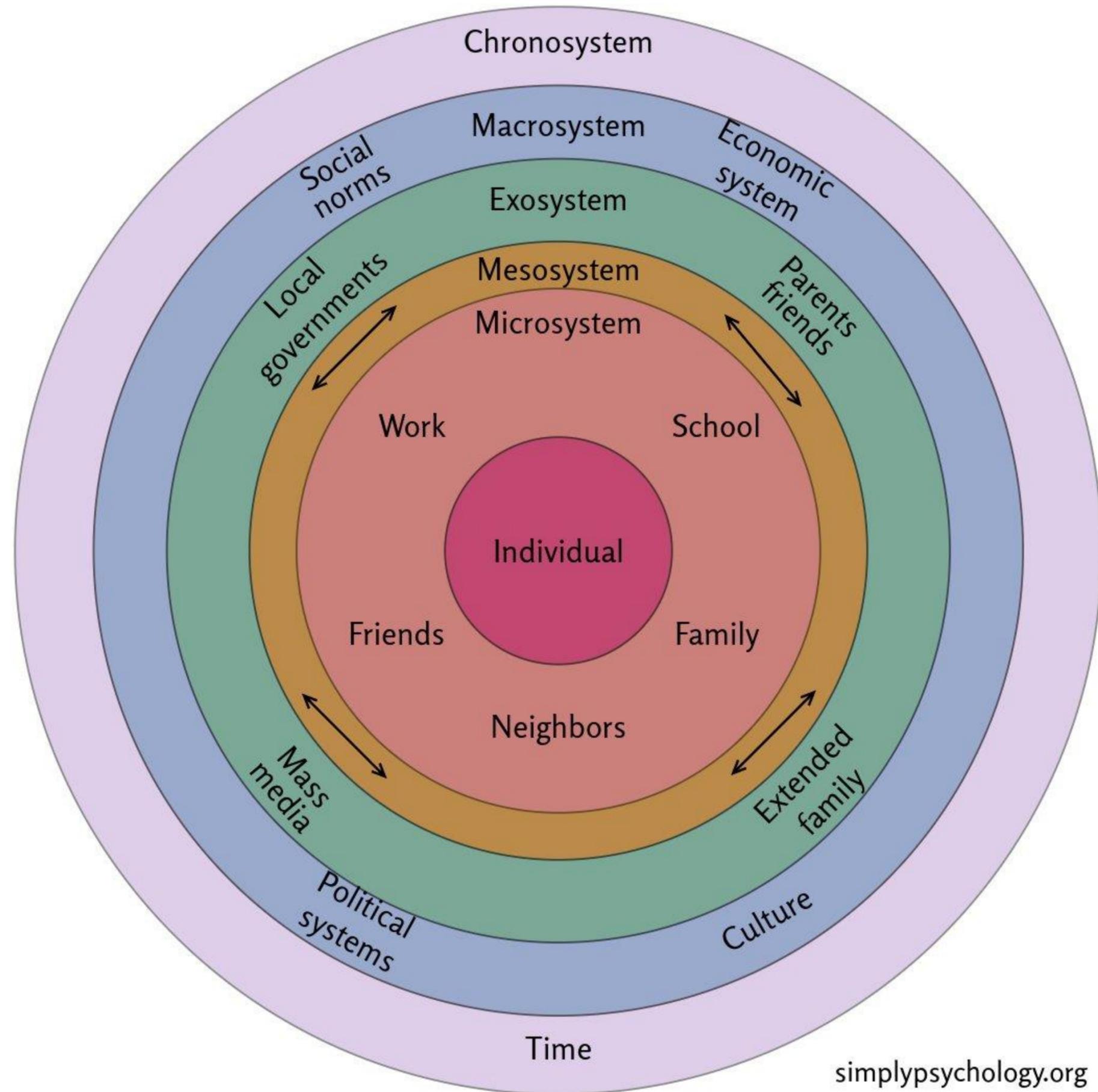
What research matters in the classroom?

- Moving beyond “fixing” the child
- Environmental fit
- Predictability and structure
- Universal design for learning

Autistic students consistently tell us that being understood matters more than being fixed.

Ecosystem of the child

Bronfenbrenner's Ecological Systems Theory



Activity – Tell us what data matter to you

What evidence would better support autistic people in your setting

- What do educators need to know
- What evidence supports accessibility
- One question per stick note

Follow through:

- Feed into the work of the Alliance and the network
- Shape future evidence products



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www.autismalliance.ca

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