Disability Policy Research Program

kids brain health network | réseau pour la santé du cerveau des enfants

ADVANCE Fellow Report Summary

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Falling Through the Cracks: Access and Exclusion in Early Childhood Disability Supports Across Canada

Working group members: Stephanie Chipeur, Genevieve Currie, Marion Knutson, Audrey McFarlane, Mandy Young
Principal Investigator: Dr. Laura Mudde

Overview

Who is missed in the uptake of early childhood disability supports, and why? This project focuses on infants and children aged 0–5 in British Columbia, Alberta, and Ontario. It draws on a jurisdictional scan, a targeted literature review, and co-produced knowledge from a six-member working group of people with lived, family, professional, and policy experience.

The central finding is that a program's existence does not mean a child and family can access it. Support is routinely gated by diagnosis, fragmented across health, childcare, disability, and education systems, and dependent on families having the time, income, and know-how to navigate it. That burden falls unevenly—and this work speaks to the federal, provincial, and territorial policymakers, program administrators, and service providers who shape those systems, as well as the families moving through them.

Key findings

Formal access and substantive access are not the same, and the gap between them falls hardest on families with the least capacity to absorb it. Diagnosis functions as the gateway:

4/5

working group members identified children without one as especially likely to miss supports, yet assessment pathways are long, unevenly distributed, and poorly suited to complex or rare presentations.

98%

of people in Canada with FASD go undiagnosed or misdiagnosed, and a single clinic in the Northwest Territories reported an estimated 4.5-year wait for assessment, a delay that, for a young child, can consume the entire early-childhood window.

Delays like these compound across the pathway, from first concern to referral, assessment, funding, and service, and age-based eligibility can turn that accumulated delay into outright exclusion before a child ever reaches a program. The families most likely to fall through the cracks are those already carrying the most: children without a diagnosis, families affected by poverty, housing insecurity, rural isolation, language barriers, racism, and colonial relations, and Indigenous, newcomer, and refugee families.

What's next?

Closing these gaps means ensuring systems function as intended, so families are not left carrying the sole responsibility of navigating fragmented services on their own. This starts with needs-based support that begins before diagnosis, using diagnosis where it informs care—not as the only point of access. Families also need coordinated entry, clear navigation, and active referral pathways, along with continuity of support across waitlists, age transitions, and service changes.

These commitments must also be properly resourced and accountable. That means investing in service capacity where it is most limited—including rural, northern, remote, and under-resourced communities—and ensuring services are culturally safe and, for Indigenous children and families, Indigenous-led and distinctions-based. Governments must also improve transparency by reporting on eligibility, wait times, denials, and service use, with clear accountability across ministries and jurisdictions—so no child's needs fall through the gaps.

Waiting to Wait: Understanding Access Trajectories of Childhood Disability Programs Across Canada

Principal Investigator: Kelsey Seguin

Working group members: Brittany Finlay, Corey Fortier, Paul Ovcacik, Stephanie Paravan, Keiko Shikako, and Olaf Kraus De Camargo

Overview

This project examines barriers to accessing publicly funded disability services for children and youth (0–18) across Canada, focusing on wait times and access trajectories across jurisdictions. National reports and caregiver-reported data suggest delays occur at multiple stages of the service pathway - diagnosis, eligibility, funding approval, and service access - and may be cumulative rather than isolated, with particularly pronounced impacts in rural, remote, and under-resourced communities.

The intended impact is to improve understanding of how system design shapes access to services and contributes to variation in wait times. This work is relevant to policymakers, service providers, health professionals, and organizations involved in disability service planning and delivery - as well as to the children, youth, caregivers, and families navigating these systems. Wait times are embedded across the structure of childhood disability service systems rather than caused by a single bottleneck.

Key findings

System-level indicators point to substantial pressure across jurisdictions. Some illustrative examples across jurisdictions include:

73%

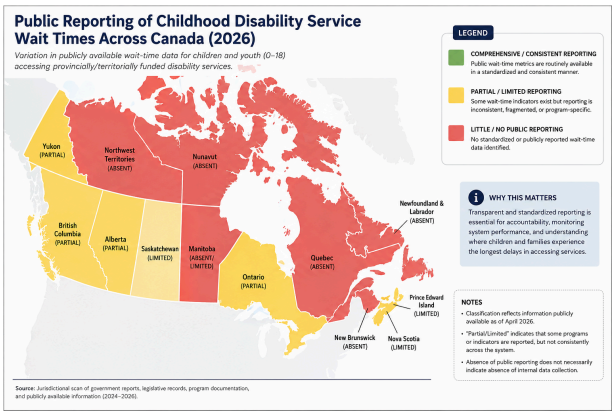
of Ontario caregivers identified long waitlists as a major barrier to accessing services. (Ontario Autism Survey, 2018 & What We Heard Report, 2025)

55k-83k

children and youth in B.C. may not be receiving required supports (BCACDI, 2025).

292

peak caseload per worker in the Northwest Territories (Health & Social Services, 2025).



What this adds

- The findings highlight how system design shapes access and contributes to uneven wait times, underscoring the need for more coordinated, equitable approaches to service delivery.
- The report compiles evidence from across Canada's provinces and territories to examine wait times throughout the childhood disability service pathway, from diagnosis and eligibility to funding and service access.
- The analysis shows how different system designs shape where delays accumulate, highlighting interactions between diagnostic requirements, administrative processes, workforce capacity, and service availability.

What's next?

- Examine how differences in system design across jurisdictions shape access pathways and contribute to wait-time variation.
- Explore opportunities to reduce fragmentation and administrative burden across service pathways, including more coordinated care models.
- Investigate how workforce capacity influences access to services, particularly in rural, remote, and under-resourced communities.
- Assess alternative approaches to diagnosis, eligibility, and funding to understand how more streamlined or parallel models could reduce cumulative delays.
- Identify characteristics of high-performing jurisdictions to better understand what supports more timely and equitable access.
- Explore caregiver experiences and navigation challenges to better understand how families move through systems and where barriers persist.

Language Matters: Exploring how Disability Definitions Shape Access to Government Disability Income Support Programs for Children, Youth and Families

Principal Investigator: Dr. Meaghan Reitzel

Working group members: Sharon McCarry, Amanda Doherty-Kirby, Cynthia Minh, Douglas Waxman, Alexi White, Jennifer D. Zwicker, & Michelle Phoenix

Overview

This project examines how disability is defined in Canadian government income support programs - and how those definitions shape equitable access for children and youth (0–25) and their families. Through a critical discourse analysis of 23 provincial and territorial programs, it explores whether policy language reflects a static, deficit-based view of disability or a more dynamic, human rights–based approach.

The goal is to shift toward a harmonized definition aligned with the UN Convention on the Rights of Persons with Disabilities (UNCRPD) - one that recognizes disability as an evolving interaction between individuals and their environments, and affirms people with disabilities as rights-holders. This work is relevant to policymakers, program administrators, advocates, researchers, and the families navigating these systems.

Key findings

A pan-Canadian scan of 23 disability income support programs revealed how deeply restrictive definitions are embedded:

22 of 23

programs rely on restrictive, impairment-focused definitions tying eligibility to deficit severity and duration.

43%

of program definitions explicitly link disability to an inability to work.

1

program adopts a human rights–based definition of disability aligned with the UNCRPD.

Definitions across jurisdictions remain largely medicalized, static, and disconnected from social and environmental realities, resulting in fragmented access; in some cases, only 25% of eligible individuals receive support. Reforming definitions is not just technical; it is a key lever to reduce stigma and advance equity.

What's next?

- Build policymakers' awareness of the misalignment between current definitions and human-rights standards.
- Advocate for adoption of a harmonized, inclusive definition of disability across jurisdictions.
- Support administrators in adopting criteria that account for environmental barriers and dynamic needs, with lived experience embedded in design and review.
- Track system-level outcomes — more consistent access rates across jurisdictions — and continue knowledge mobilization through symposia and community webinars in Canada and internationally.

Voices from the Working Group

- "It has been amazing to see the diverse ideas and perspectives brought forward from the working group. This helped us keep the potential impact on the lives of disabled people and their families at the forefront of our minds while moving through data collection, analysis, and knowledge sharing."

- "As a parent of multiple children with various disabilities, it has been both encouraging and frustrating — encouraging to be part of something that could change how things are done, and frustrating to realize once again that access to support depends so much on deficit-based thinking and one's postal code. This work encouraged me to advocate more for equitable benefits, and I am hopeful for a future where children and youth with disabilities and their families are supported in a way that enables living, learning, and growing."

- "As a trainee in disability policy research, working alongside members with such diverse and extensive experience was an invaluable learning opportunity. By keeping the 'so what' and 'what's next' at the forefront, we aimed to frame actionable recommendations with the potential to shift the disability policy landscape in Canada."

- "As Co-Director of the ADVANCE Network and a person with lived experience, this project was both professionally and personally meaningful. Four years as a member and Co-Chair of the CRA's Disability Advisory Committee showed me firsthand how definitions determine whether families can access the benefits they need. Our collaboration reinforced my belief that research is strongest when lived experience is valued as expertise."

A Cross-Jurisdictional Mapping of Developmental, Disability and Early Childhood Intervention Systems in Canada: Ministerial Structures, Service Coordination, and School Transition

Principal Investigator: Dr. Sarah Raza

Working group members: Lucyna Lach, Logan Wong, Amber Mack, Becky Conia, Sabrina Eliason, Lee Pigeau

Overview

Young children with developmental concerns, disabilities, or support needs often require programs and services that span health, education, childcare, and social service systems. In Canada, responsibility for these developmental and early intervention supports rests primarily with provincial and territorial governments, resulting in substantial variation in how services are organized, delivered, and coordinated. Understanding these differences is essential for identifying opportunities to improve continuity of care, reduce navigational burden for families, and support children's successful transition into school.

This report presents the findings of a cross-jurisdictional mapping of developmental, disability, and early intervention programs and services for children from birth to approximately six years of age across all 13 Canadian provinces and territories. Using publicly available policy and program information, the study examined governance structures, ministerial responsibilities, eligibility approaches, transition processes, and care coordination mechanisms. A participatory Working Group – comprising individuals with expertise in disability policy, early childhood services, research, advocacy, and lived experience – informed the project's scope, analysis, and interpretation. A total of 71 developmental, disability, and early intervention programs and services were identified across Canadian jurisdictions

Key findings

1. **Fragmentation is universal, but its form varies.** Responsibility for developmental, disability, and early intervention supports is distributed across multiple ministries in every jurisdiction. While governance structures differ across jurisdictions, fragmentation was not determined solely by the number of ministries involved. In several jurisdictions, some of the most significant disconnects occurred within ministries rather than between them, highlighting the importance of coordination mechanisms in shaping how families experience services.

2. **Supports exist across the continuum of care, but continuity is uneven.** All jurisdictions offered developmental and disability supports ranging from developmental screening and early identification to targeted intervention and specialized rehabilitation services. However, no province or territory demonstrated a fully integrated continuum in which children and families could move seamlessly between levels of support. Families frequently encountered separate programs and services with different eligibility requirements, service pathways, and transition processes.
3. **Needs-based and diagnosis-based approaches to access coexist.** Many early intervention programs allow children to access services based on developmental concerns or functional needs. In contrast, several specialized programs require a confirmed diagnosis before services can be accessed. These differing approaches have important implications for when children receive supports and may contribute to inequities associated with assessment wait times and service availability.
4. **School entry is a critical point of system discontinuity.** The transition from early childhood services into kindergarten emerged as one of the most significant structural challenges identified. In many jurisdictions, responsibility for services shifts between sectors at school entry, while formal mechanisms to support continuity remain limited. More structured transition approaches were identified in jurisdictions such as New Brunswick, Manitoba, Ontario, and Quebec, demonstrating that greater continuity is possible within a range of governance arrangements.
5. **Formal care coordination remains limited.** Although developmental and disability support systems require families to navigate multiple ministries, programs, and providers, centralized navigation and care coordination mechanisms were uncommon. In most jurisdictions, families remained the primary coordinators of services. Examples from Quebec, Ontario, and New Brunswick demonstrate that coordinated entry points and integrated service models can help reduce navigational burden and improve continuity across systems.

What this adds

- This report provides a comprehensive cross-jurisdictional mapping of developmental, disability, and early childhood intervention systems across all 13 Canadian provinces and territories. Although services are available across Canada, children and families often experience them as separate and disconnected systems. **The findings suggest that the most important difference between jurisdictions is not how many programs they offer, but how effectively ministries, sectors, and programs work together to create coordinated pathways of support.**
- **Key Policy Takeaway:** Taken together, the findings suggest that improving developmental and disability support systems may depend less on creating new programs and more on strengthening connections between existing ones. While services are often available, they are frequently fragmented—making coordination, continuity across transitions, and reduced barriers to access key opportunities for improvement. Ultimately, system effectiveness depends not only on what services exist, but on how well ministries, sectors, and programs work together—making coordination as critical as expanding services.