

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

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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.