Policy Research Brief

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Developing the Canadian Health Indicators for chiLDren with Disabilities (CHILD): A Wellbeing Measure for Canadian Children with Disabilities

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Research area studied: Health systems & policy
Keywords: children with disabilities, wellbeing, data, policy

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KEY MESSAGES

1) Policy priority studied: **Children with disabilities in Canada face significant disparities** in health, social inclusion, access to education, and support services compared to their peers. With **inadequate measurement and tracking of their wellbeing**, current policies may not address their needs. Closing this gap is essential to advancing health equity and improving outcomes for this equity-deserving group.

2) Approach used: We conducted a **rapid synthesis of global and national wellbeing frameworks**, **stakeholder consultations, and interviews** with youth, families, and experts to develop an **evidence-informed and contextually relevant wellbeing indicators framework for children with disabilities in Canada**: the Canadian Health Indicators for chiLdren with Disabilities (CHILD). We then conducted a **review of population-based datasets from Statistics Canada** to identify the indicators that are currently measured and data gaps.

3) Key findings: Comprehensive disaggregated data on children with disabilities in Canada is lacking. Critical data gaps include:

- Access to services, housing, green spaces and social and economic security, particularly for children under 15 years old.
- Information about inclusive education, health services, supports and social participation.
- Impact of disability on families, caregivers, and communities.

The CHILD framework offers a comprehensive list of well-being indicators, including physical and mental health, access to services, social participation, and social and economic security. We recommend the use of the CHILD to expand Canada's Quality of Life Framework integrating it into national data collection systems, and implementing targeted policy initiatives to improve cross-sectoral coordination and support for children with disabilities and their families.

Policy issue

- Lack of comprehensive indicators on the wellbeing of Canadian children with disabilities to inform policies.
- This research supports the Quadruple Aim by:
    - meaningfully engaging multiple stakeholders
    - Generating needs-based solutions that are data-driven and can improve health outcomes by adequately measuring and targeting structural and social determinants of health for children with disabilities in Canada.

Policy research approach

- Integrated Knowledge Translation (IKT) approach:
    - Rapid evidence synthesis,
    - Expert consultations
    - Key informant interviews (youth with disabilities, their families, healthcare providers, policymakers, and disability advocates).
    - Analysis of Statistics Canada existing datasets representing the theoretical framework indicators.

Policy research findings

- Comprehensive disaggregated data on children with disabilities in Canada is lacking. Critical data gaps include:
    - Access to services, housing, green spaces and social and economic security, particularly for children under 15 years old.
    - Information about inclusive education, health services, supports and social participation for children and youth of all ages.
    - Impact of disability on families, caregivers, and communities.

The CHILD framework offers a new, comprehensive set of indicators that can fill these data gaps and provide a foundation for more targeted policy interventions. It emphasizes the need to move beyond a medical model of disability to one focused on human rights, inclusion, participation, and the social determinants of health, ensuring children with disabilities are fully represented in Canada's wellbeing agenda.

Evidence-informed policy options

1. **Status Quo Option**:
   Maintain existing data collection systems without specific adaptation for children with disabilities. While administratively simple, this option leaves gaps in understanding and addressing their needs. It risks perpetuating health inequities and service fragmentation, with negative long-term effects on child outcomes.
2. **Gold Standard Option**:
   Fully implement the CHILD framework into data collection systems, including indicators for the general child population that are disaggregated for children with disabilities, and distinct indicators for children with disabilities. This option allows for robust tracking of wellbeing, ensuring coordinated policy interventions across jurisdictions, focusing on inclusion and access. Though resource-intensive, it would lead to more equitable outcomes, reduce long-term healthcare costs, and improve quality of life for children with disabilities. Key considerations include funding, cross-sectoral coordination, and stakeholder engagement, particularly with policymakers and child disability advocacy groups.
3. **Alternative Option**:
   Gradually incorporate key CHILD indicators into existing data frameworks, beginning with essential areas such as healthcare access, education, and participation. This approach is more feasible economically and administratively. It allows time for stakeholder adjustment and resource allocation but may delay broader, long-term improvements in wellbeing tracking and service provision for children with disabilities.

Quotes illustrating the relevance of the CHILD framework:

Importance of indicators: *"Economic prosperity, poverty reduction. Yeah, very important. We know that there are a number of people with disabilities living in poverty or having difficulties finding employment. And so I think that would be quite important to track, especially at the young teenage transitioning ages."(key informant interview participant)*

"I mean, again, I think one of the biggest indicators for a child with an intellectual disability's quality of life is their early learning and education... If a kid is in an inclusive daycare or an inclusive kindergarten and then goes to inclusive elementary and keeps going and is actively included in that school community, they are more likely to graduate and get a job, they're more likely to have inclusive employment as an adult. They're more likely to move out into inclusive housing. But if a kid is segregated at the beginning in the education system, they're more likely to graduate into a sheltered workshop where they don't get paid. They're more likely to live in a group home or like a large-scale institution. It is the single most, it's one of the single, like largest indicators of whether or not a person is going to live an inclusive life (key informant interview participant)

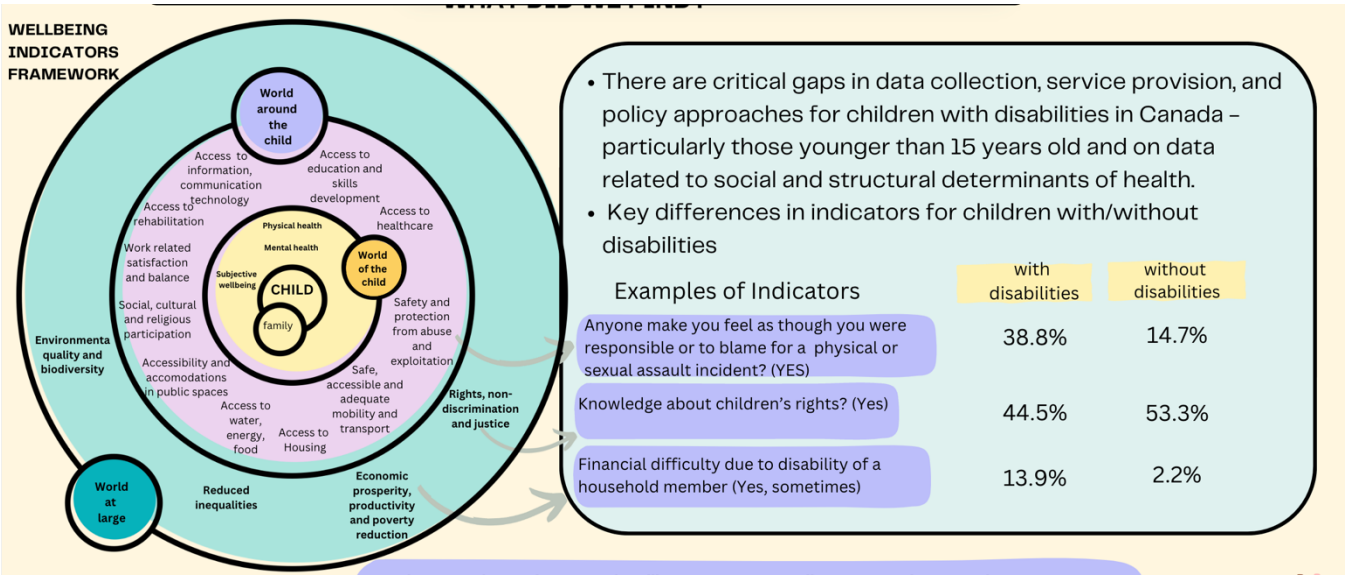
Implications for research, policy, and practice

Key implications:

The CHILD framework can enhance health equity by addressing the unmet needs of children with disabilities and improving access to services. Integrating these indicators into national data collection systems will support policymakers and healthcare providers to deliver targeted interventions, improve child outcomes and reduce healthcare costs. It supports the Quadruple Aim by enhancing patient experience and population health.

1. **Next steps**:
   Next steps include scaling this framework into policy, integrating CHILD indicators into existing national data collection systems, engaging provincial and federal stakeholders for cross-sector collaboration, and securing funding. Building stakeholder consensus on the meaningfulness and appropriateness of these measures is essential for a coordinated rollout.
2. **Research needs**:
   Future research should focus on longitudinally tracking CHILD indicators, and explore the intersectionality of disabilities with factors like income and geographic location. Expanding the framework to include other vulnerable populations presents an opportunity to improve health equity broadly – including indigenous children and youth with disabilities, LGTB+ children and youth with disabilities, and data collection structures that capture the experience of disabilities in communities and across sectors and jurisdictions.

Canadian Health Indicators for chiLDren with Disabilities (CHILD)



OUTPUTS & PRODUCTS **(optional)**

Output 1: https://www.canva.com/design/DAGS2iSiS5A/uvAp0jLpFPCaGlPUvpnNgQ/view?utm_content=DAGS2iSiS5A&utm_campaign=designshare&utm_medium=link&utm_source=editor - Click or tap here to enter text.

Output 2: https://www.childhooddisability.ca/child/ - Click or tap here to enter text.