



CHILD-BRIGHT: Mobilizing Knowledge for Impact

Federal leadership is urgently required to measurably improve the health and well-being of Canada’s children and youth. Inspiring Healthy Futures (supported by cross-sector champions for children, youth and families) identifies five key priorities for action: impactful research & knowledge, child-centred policies and structures; schools and communities as hubs of health and well-being; accessible, adaptable health systems; and mobilized communities around children, youth and families. Given the consideration of a child health strategy/framework, we wish to raise awareness of CHILD-BRIGHT, a Canadian Institutes of Health Research (CIHR) funded Strategy for Patient-Oriented Research (SPOR) network.

CHILD-BRIGHT has developed a movement for change for children and youth with brain-based developmental disabilities and their families: centering patients in research teams, moving research into improved practice and policy, and moving children and families forward to brighter futures. Our network activities can be leveraged to overcome barriers to health research, tackle health service backlogs through novel service delivery models and supports for families, address disparities in access to services, and foster partnerships to address health human resource challenges.

What is the CHILD-BRIGHT Network

The CHILD-BRIGHT Network is a pan-Canadian patient-oriented research network. Created in 2016, it works to create brighter futures for children and youth with brain-based developmental disabilities and their families. Funded by the CIHR under Canada’s SPOR initiative and 15 funding partners across the country, the national network includes 350 researchers, clinicians, decision-makers, youth, and parents. CHILD-BRIGHT’s extensive research program was developed based on research priorities identified by youth, parents, and other knowledge users such as frontline clinicians, and health care administrators. From 2016 to 2022, CHILD-BRIGHT carried out 13 multi-centre projects focusing on three themes: early intervention to promote brain and child development; strategies to support the mental health of children and families; and service delivery redesign to address gaps in service. From 2022 to 2026, CHILD-BRIGHT will move its patient-oriented research into action through insight and methods grounded in implementation science and knowledge mobilization, and by embedding the principles of equity, diversity, inclusion, decolonization and Indigenization.





Who does CHILD-BRIGHT help

In Canada, as many as 850,000 children are living with a brain-based developmental disability and face life-long challenges with mobility, language, learning, socialization, and/or self-care that impact the quality of life of the child and the family. CHILD-BRIGHT works to make the future brighter for infants, children, and youth with lifelong brain-based developmental disabilities and their families. This includes individuals with a diagnosis of a brain-based disorder (e.g., autism spectrum disorder, attention deficit hyperactivity disorder, fetal alcohol spectrum disorder, cerebral palsy, intellectual or learning disabilities), and individuals at high risk for a brain-based disorder (e.g., preterm birth, congenital heart disease, genetic anomaly).



<p>1 IN 12 children have learning disabilities</p>	<p>1 IN 13 children are born premature</p>	<p>1 IN 20 children have difficulties that impact their day-to-day lives or functioning</p>	<p>1 IN 50 children have autism spectrum disorder</p>	<p>1 IN 400 children have cerebral palsy</p>
<p>Every child also has a family</p>				

CHILD-BRIGHT Phase 1 accomplishments (2016-2023)

During CHILD-BRIGHT’s first phase of funding, the network established its infrastructure, brand, governance, programs, and research. Over the course of this period, in collaboration with network partners and a growing community of knowledge users, we created positive changes for children with brain-based developmental disabilities and their families. Some are detailed below:

For children and youth with brain-based developmental disabilities

- Developed and executed 13 innovative patient-oriented research projects dedicated to improving the health and well-being of children and youth with brain-based disabilities.
- Created spaces for youth voices in research by developing the CHILD-BRIGHT National Youth Advisory Panel, a panel of youth who have lived experience with a brain-based developmental disability and inform research development and dissemination throughout the network.
- Launched an external consultation service for researchers.



For parents and families

- Fostered meaningful patient engagement, notably through the creation of the CHILD-BRIGHT Citizen Engagement Council, composed of parents and caregivers with experience or with a child with brain-based developmental disabilities.
- Embedded patient-partners and parent-partners in research and governance to augment patient voices in decision-making.
- Launched patient engagement measurement strategies to inform ways of authentically involving youth and parents in our network’s activities.

For the next generation of patient-oriented researchers

- Created a network patient-oriented research summer studentship program.
- Supported graduate student fellows in pediatric neurodevelopmental research.
- Launched funding opportunities to grow national patient-oriented research capacity.
- Collaborated with key partners to develop the Patient-Oriented Research Curriculum in Child Health (PORCCH), a series of online and self-directed modules aimed at enhancing the ability of all interested parties to engage in patient-oriented research.
- Collaborated with SPOR-funded entities to develop a National Training Entity in patient-oriented research.



For policy makers & other groups

- Engaged with researchers and knowledge users to explore new strategies to implement and disseminate CHILD-BRIGHT’s research findings.
- Hosted two policy forums to connect policy makers from across Canada with patient-partners, service providers, and researchers to tackle important issues related to the care of children and youth with neurodevelopmental disabilities.
- Developed a Policy Hub dedicated to responding to the knowledge needs of policy makers relevant to children with developmental disabilities.



CHILD-BRIGHT Phase 2 objectives (April 2022-March 2026)

From 2022 to 2026, CHILD-BRIGHT strives to move forward for impact. The network will use its new funding to create some urgently needed infrastructure and capacity in knowledge mobilization and implementation science. **Knowledge mobilization** refers to providing evidence and knowledge to appropriate people when they need it, and in a format that is suitable to them. **Implementation science** is a field of research that studies how a novel, evidence-based intervention will interact with real-world settings with the ultimate outcome of understanding what needs to be in place for the intervention to succeed in practice and at scale.

CHILD-BRIGHT Phase 2 programs

- The **Implementation Science Research Program** will focus the network’s research to better understand how evidence generated in Phase 1 can be systematically applied in routine practice to improve quality and effectiveness of health services, community programs, and policy.
- The **Equity, Diversity, Inclusion, Decolonization and Indigenization (EDI-DI) Program** will deploy initiatives to ensure a culturally safe environment and that EDI-DI principles are authentically embedded in our four other programs, our governance structure, and the research conducted by the network.
- The **Training & Capacity Building Program** will continue developing capacity in patient-oriented research with new curricular content that will emphasize topics related to understanding and applying implementation science and knowledge mobilization methods and EDI-DI principles in patient-oriented research.
- The **Citizen Engagement Program** will continue to monitor and enhance citizen partnerships and will assume leadership nationally in promoting patient-oriented research in child health research. The citizen engagement team will work closely with the EDI-DI Program to engage citizens (patient-partners and other groups) who are underrepresented in the network, and ensure our compensation models are commensurate with CHILD-BRIGHT’s evolving compensation guidelines.
- The **Knowledge Mobilization (KM) Program** will influence practice and policy by building an infrastructure that will facilitate direct knowledge exchange with targeted users (patients and families, health care providers, decision-makers, community) using tailored, evidence-informed, user-friendly strategies and by systematically evaluating impact.



Why knowledge mobilization matters

“If we want to effect real change in the health care system, knowledge mobilization needs to be informed by all the groups involved: from the ‘end-users’ (patients, families) to the ones delivering health care (health care providers and community organizations) up to the ones making decisions about health care systems, budgets, and priorities (decision-makers).”

Dr. Keiko Shikako, Knowledge Mobilization Program Co-Lead



“Contributing to research can be a healing experience for families who have gone through a difficult health journey. Knowledge mobilization from the family/patient perspective is enhancing the evolution of research and making it more accessible for both the researcher and families.”

CHILD-BRIGHT Patient-Partner

Youth and parent-partner involvement in our various activities continue to be crucial as it brings different valuable perspectives to our efforts and informs the way we design and implement our implementation science projects and knowledge mobilization products.

CHILD-BRIGHT can contribute to a Pan-Canadian Children’s Health Strategy guided by four principles:

- **Interdependence:** The health and well-being of children, youth and families will only be achieved through address of all five interlinked priorities defined by Inspiring Healthy Futures.
- **Equity:** Children and youth in racialized, Indigenous or marginalized communities, gender diverse and LGBTQ2+ youth, and those with disabilities are at a severe disadvantage. Principles of equity and ultimately justice must underpin a pan-Canadian child health strategy.
- **Collaboration:** A great deal of knowledge, evidence, and innovation is underway in Canada. A pan-Canadian child health strategy must identify opportunities for collaborative action and engagement. The power of collaboration is demonstrated every day in the CHILD-BRIGHT Network.
- **Youth and family participation:** Youth are critical and willing partners to effect change and execute meaningful action. They must be engaged in the development and implementation of a pan-Canadian child health strategy. Our National Youth Advisory Council and our Citizen Engagement Council are ready to engage!



CHILD-BRIGHT recommendations and considerations

The CHILD-BRIGHT Network team respectfully requests that the Federal government consider:

1. The need to sustain this SPOR network beyond the short-term renewal period of April 2022 to March 2026
2. The need for continued research funding in the area of brain-based developmental disability in children and youth
3. Health research funding that takes a “life-course” approach, with attention paid to the health of children and youth across the entire CIHR portfolio
4. Attention to ability and disability in all considerations of equity, diversity and inclusion.