

**Ensuring Optimal Care and Better Outcomes for Children with
Neurodevelopmental Disabilities in Canada**

**Written Submission for the Pre-Budget Consultations
in Advance of the Upcoming Federal Budget**

By: Kids Brain Health Network



Summary of Recommendations

Kids Brain Health Network makes the following recommendations to the government:

Recommendation 1: That the government provide funding in the amount of \$50 million over 5 years to ensure and implement early identification, optimal care and better outcomes for children with neurodevelopmental disabilities in Canada through the work of the Kids Brain Health Network (KBHN).

Introduction

Approximately 10% of Canadian Children between the ages of 4-11 years of age have a neurodevelopmental disability (NDD), such as Autism Spectrum Disorder, Cerebral Palsy, Fetal Alcohol Spectrum Disorder, Attention Deficit Hyperactivity Disorder, and Intellectual Disability. The need to move evidence into practice to improve early diagnosis, optimal treatment and family support, especially for Indigenous children with NDD, is met through the work of the Kids Brain Health Network (KBHN). KBHN is a national network that works through partnerships and leverage with public and private sector organisations to develop scientific advances in technologies and interventions for kids with NDD. It has a unique role in implementing change for Canadian kids with NDD.

Many children with a neurodevelopmental disability are unable to reach their full potential. This happens because provincial and federal government services and systems lag behind scientific advancements that have highlighted the crucial importance of the early years in brain development. These services need to be modified to address the individualized needs of children with NDD and their families. Lack of access to services and professional supports spanning health, education, and social services have life-long implications. These deficiencies impact child and adolescent development and child and family quality of life for the 90% of individuals with a neurodevelopmental disability who need this support. This does not have to be the case.

There is much more to do to ensure that every child with a neurodevelopmental disability receives the support they need to reduce barriers and to thrive. Innovations and advancements in core challenge areas present opportunities to enable reaching the full potential for healthier kids, healthier families, and social and economic benefits to Canada.

Through catalyzing collective action across sectors, KBHN's mission is working to ensure optimal care and better outcomes for children with neurodevelopmental disabilities and their families. KBHN's unique approach is to bring Canada's leading researchers together with families and communities to develop interventions that are scientifically effective, culturally relevant, and bridge the gap between scientific discovery and the families who need it most. KBHN builds and adapts implementation, commercialization and engagement processes that accelerate the pace of innovation to impact.

KBHN is a leader, enabler and facilitator of initiatives that give families hope. Its work empowers parents and caregivers to help NDD kids learn and develop with science-based tools. The science of children's brain health is making advancements and while solutions exist, innovations and advancements often don't make it to the children and families who need them. KBHN is uniquely bridging the gaps between these scientific advances and implementing solutions that directly address the needs of children and families.

In delivering its mission, KBHN is advancing federal responsibilities and priorities aimed at building a healthier future for children and families, building a barrier-free country and

accelerating the pace of implementation, scale and spread of research innovations to unleash their full potential for healthier kids, healthier families, and social and economic benefits to Canada.

We are eager to work with government to help ensure optimal care and better outcomes for children with neurodevelopmental disabilities in Canada.

Justification for Funding

KBHN was originally funded as part of the Networks of Centres of Excellence (NCE) initiative, which was run by the federal government and funded partnerships between universities, industry, government, and not-for-profit organizations to create large-scale research networks. In December 2018, the NCE initiative began to wrap up with a partial funding transition to the New Frontiers in Research Fund (NFRF).

KBHN is a not-for-profit organization and research network. It has a proud record of leveraging support through public and private sector partnerships but it is ineligible to apply for funding programs offered through granting councils (CIHR, NSERC, SSHRC) or the NFRF. Regardless, there continues to be great advancement in the science of children's brain health. Hence KBHN has a critical role to play in addressing the implementation gap, helping children with neurodevelopmental disabilities and their families.

As such, KBHN is asking the federal government for funding in the amount of \$50 million over 5 years to ensure optimal care and better outcomes for children with neurodevelopmental disabilities in Canada.

Importance of Funding

No other organization in Canada shares KBHN's mandate and ability to bridge the gap between science, new innovations, building community partnerships and implementation practice, scale and spread for this population. This government funding is critical to realize partner funding contributions. By connecting leading researchers in Canada with front line organizations that deliver supports and services directly to children and families, and to industry partners and investors who can commercialize research innovations to go out to market, KBHN accelerates the translation and uptake of new discoveries for social and economic benefit. KBHN delivers real results which enables a healthier future for all our kids.

By reaching children and their families at the earliest possible age with the very best assessment tools, innovations, and interventions, research has demonstrated that we can have a major impact on brain development, thus mitigating the long-term costs to social services, health care, education, corrections, and supportive housing.

KBHN is achieving its vision of helping kids with neurodevelopmental disabilities reach their full potential by:

- Maintaining the only national cross sectoral network in Canada, and an exemplar internationally, connecting families, researchers, innovators, service providers, decision makers and stakeholders to identify issues and develop practical evidence-based solutions for kids and their families.
- Innovating and accelerating the implementation, commercialization and scale up of interventions, innovations and supports, so the benefits reach kids and families faster.
- Embodying “Nothing About Us Without Us” as the national and international leader in family engagement in research, co-designing with youth and families to ensure that innovations and interventions are informed by families’ experiences and guided by the needs of kids from the start, through development and implementation.
- Fostering a culture of accessibility, equity, diversity, and inclusion through engagement with a broad network of research and partner communities.

Finally, securing funding from the federal government would help fulfill the objective to advance federal responsibilities and priorities aimed at:

- **Building a healthier future for children and families:** KBHN is the only national network in Canada positioned to deliver on its mandate for children with neurodevelopmental disabilities and their families.
- **Building a barrier-free country:** KBHN is uniquely positioned to apply an intersectoral lens to advance the federal government’s accessibility priorities and responsibilities, ensuring engagement of children and youth with neurodevelopmental disabilities and their families in the development of evidence-informed disability-inclusive laws, policies, and programs.
- **Accelerating the pace of implementation, scale and spread of research innovations to unleash their full potential:** brings the often-overlooked child health and accessibility lenses to the broader research and innovation ecosystem and, in addition, has an internationally recognized track record of research and training excellence.

Important Progress Made as a Direct Result of Kids Brain Health Network

From identifying the issue, to putting the innovation into practice and scaling it, KBHN’s approach catalyzes available evidence-based solutions, making them accessible to those who need them. KBHN research initiatives are making a real difference in accessing early identification, evidence-based interventions and services, and family support benefiting children and families.

Since 2010, KBHN has invested more than \$77 million in over 200 programs that focus on early identification, early intervention and family support. These include flagship innovations such as:

- **The Social ABCs Program** – an evidence-based parent-guided program for toddlers with confirmed or suspected autism designed for parents to use in natural interactions with their kids at home. The Social ABCs program entails coaching parents to consistently utilized play-based strategies, designed to foster the development of social and communication skills in their daily interaction with their young children. Empowering parents as the active agents of change for their toddlers, as early as possible, can significantly enhance children’s outcomes and mitigate parental stress.
- **Dino Island** – a therapeutic video game grounded in 30 years of applied research and clinical trials that treats common executive functioning and attention issues in kids with neurodevelopmental disabilities. The program is accessible and can thrive in a wide range of settings (i.e., school, home, and community settings). It breaks down barriers by allowing remote and resource-limited communities to address needs that might otherwise go unmet. The Dino Island Tablet consists of five video games, each designed to improve attention, short-term memory, and self-regulation (executive functioning) while kids feel like they’re playing a video game.
- **Acceptance and Commitment Training (ACT)** – a mindfulness-based psychological intervention aimed at increasing psychological flexibility through training in six core processes: diffusion, acceptance, contact with the present moment, self-as-context, values, and committed action. It consists of a series of experiential exercises, mindfulness practices, and small and large group reflective sharing guided by trained co-facilitators. The principles of ACT have also been adapted for Indigenous professionals and community helpers to bring together traditional teaching of Indigenous Knowledge Keepers and an ACT stance to support First Nations, Inuit and Métis individuals who may be struggling with difficult thoughts or emotions.
- **Nurturing the Seed** – a developmental support program for Indigenous children and their families. The program was developed in partnership with Indigenous Practitioners and Elders from across Canada and it incorporates world views, values, rituals and parenting practices distinct to Indigenous communities in Canada. It also contains guidelines to help frontline workers who are non-Indigenous build the sensitivity and aptitude they will need to deliver the program. Practitioners work with families to understand a child’s development and identify areas in which a child requires additional support before creating a Developmental Support Plan with strategies to support a child’s development and reduce their stress.

No other organization in Canada has the proven track record and combination of skills and attributes that are critical for bridging the gap between knowledge creation and implementation into practice that will lead to improved outcomes for all children with neurodevelopmental disabilities and their families regardless of their background. Over its 13-year history, KBHN has attracted partnership funding of more than \$47.5 million, representing close to 100 per cent leveraging of Canada’s ST&I investment through the NCE program. By March 2024, partner

contributions will surpass the ST&I investment. KBHN's network includes 22-member institutions representing Canada's leading research-intensive universities and institutes, 480 principal investigators and collaborators, more than 1050 trainees and technical staff and over 270 non-academic partner organizations spanning the private, public (including federal and provincial departments and ministries), and not-for-profit sectors. Between 2010-2023 there have been over 700 KBHN publications of which 75% were published in the high impact journals and cited over 15,000 times.

The KBHN-supported research programs have generated dozens of innovation deliverables, including eHealth platforms, interventions and treatments, technological breakthroughs, new clinical practice guidelines, and training packages that are the subject of patent applications, copyright and trademark protection. Provincial Ministries across Canada are funding access to KBHN-developed interventions and programs for children and families.

This funding will be vital to allow KBHN to continue translating scientific discovery into practical, evidence-informed, and easily accessible practices, products, and policy changes, so that these discoveries continue to benefit the children and families who need them.

Conclusion

KBHN urges the government to implement the recommendation set out in this submission as part of advancing important federal priorities and fulfilling mandate responsibilities assigned to the Ministers of Health; Mental Health and Addictions; Diversity, Inclusion and Persons with Disabilities; Families, Children and Social Development; Women and Gender Equality and Youth; Innovation, Science and Industry and Crown -Indigenous Relations.

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