





THE CHALLENGE

Kids with neurodevelopmental disabilities and their families face every challenge imaginable. Everyday activities — like eating, sleeping, playing, and learning — can be extremely difficult.

Parents and families live with stress and feel isolated. Many also face financial hardship.

The COVID-19 pandemic has made everything worse, exposing deep cracks in the system. Parents are doing more on their own. For many families, what was an extremely difficult situation before is now a crisis. The pandemic has stalled or reversed progress for many kids, setting them back months or years.

The need to provide solutions — and to do it fast — has never been greater.

Fortunately, solutions are out there. The science of children's brain health is making real progress. And KBHN helps drive it forward by bridging the gaps between science and implementation.

of kids with NDDs struggle with sleep.

82%

of Canadian parents of children with autism spectrum disorder say they need more information about services that could help their families.

of people living with FASD face debilitating mental health disorders.

of kids under 14 in Canada
are living with a
neurodevelopmental disablilty
– such as autism, FASD or
cerebral palsy.

Parents tell us that **systems are difficult to navigate** and the wait times for diagnosis and support are long.

OUR FOCUS

The Kids Brain Health Network is working together with families, organizations, innovators and professionals to create a shared understanding and sense of responsibility to help kids reach their potential.

We're bridging the gap between scientific discovery and the families who need it most. Our work helps kids live their best lives and eases the burden for families.

No other organization does what Kids Brain Health Network does.

KBHN advances solutions that help kids with neurodevelopmental disabilities by focusing on their early years. We partner with key people and organizations who work directly with kids and their families, making sure evidenced-based solutions get into the hands of those who need them.

And we involve families and kids from the start, and make the science work for them. They're part of the journey, from identifying the issue to putting the innovation into practice.



At KBHN, we:

- Connect with families, researchers, innovators and stakeholders to identify issues, develop practical, evidence-based solutions and bring them to kids and their families.
- Integrate families into solutions ensuring that interventions are informed by families' experiences and guided by the needs of kids from the start.
- Bring solutions closer to implementation. We work to speed up and scale up projects, so the benefits reach kids and families faster.
- Maintain an unparalleled network across Canada, connecting scientists, families, and community stakeholders in our shared mission: putting science to work to improve the lives of kids with neurodevelopmental disabilities.
- Train the next generation of researchers in the science of implementation to help support knowledge translation and family engagement.
- Advocate for evidence-based supports and policy changes to help kids with neurodevelopmental disabilities reach their full potential.
- Promote equity, diversity, and inclusion recognizing that systemic racism and discrimination has caused historic and continuing harm to Indigenous, Black, and LGBTQ+ families and children.



OUR IMPACT

Since 2010, we've invested over \$60 million into 150 projects and research initiatives that are making a real difference – and we're working to push them out to benefit more children and families.

KBHN gives families hope and real solutions. We empower parents and others with science-based tools to help kids learn and develop. We make science work for parents, turning new discoveries into practical solutions that families can use every day.

KBHN's innovative and data informed work made us the first national network in Canada to focus on kids' brain development and neurodevelopmental disabilities.

Over the last 12 years, KBHN has been a part of many revolutionary projects. The following are just a snapshot of that work. We've got many more projects underway, and we're excited to see what comes next.

Infant and Early Mental Health Hub (Nurturing the Seed) — Developed in consultation with First Nations communities across Canada, Nurturing the Seed is a culturally-informed developmental support plan designed to meet the specific needs of infants and young children in Indigenous communities who are at risk for developmental delay. We've connected with nine Indigenous communities and more than 300 frontline service providers through an intensive coaching and mentoring program. Thousands have participated in online webinars and lecture series. Work is underway to make the program more broadly available through an e-learning platform, supporting care workers and helping them incorporate the science into their practice.

Dino Island — A cognitive intervention game that helps improve attention and executive function in children with neurodevelopmental disabilities. Studies of early iterations of Dino Island in children with ASD, FASD and other neurodevelopmental disabilities showed significant gains in attention, memory, self-regulation, emotional/behavioural control, self-efficacy, use of problem-solving strategies, and academic performance. More than 2,000 families have benefited from Dino Island.

Social ABCs — An intervention program that targets 18- to 30-month-olds with language delays or early signs of autism to help them improve verbal capacity and cope with social interactions. Studies have shown children make significant progress through this program. More than 200 families have participated since 2016 and over 800 professionals have been trained. The Social ABCs program is currently available in Ontario and PEI.

The Fetal Alcohol Resource Program (FARP) —

A community partnership focused on supporting individuals and families affected by FASD by facilitating access to regional services and providing training for more than 4,500 justice, education, health and community services professionals. FARP has provided direct clinical support, system navigation and family support groups to over 700 individuals and families.

Integrated Navigational Resources Program —

Parents told us finding their way through complex multi-sectorial service systems is one of their biggest frustrations. This program ensures that families get the help they need to navigate complex systems by shifting the onus from the parent to the appropriate professional or authority. For example, in BC over 900 families of children newly diagnosed with autism have more seamless access to supports, and in Alberta 285 parent peer mentors have received training to better support families' navigational journey.



[FARP] has by far been the most valuable resource since we first began to wonder if our daughter had FASD. They have helped us educate our daughter's school about her brain injury and how they can best support her. They have come to school meetings and directed us to resources; they have offered a support group where we can truly be understood! And most of all they have made us feel less alone in walking what can be an extraordinarily difficult journey."

A PARENT OF A 9-YEAR-OLD DAUGHTER WITH FASD

OUR MISSION

Together, we give families hope — so they know they're not alone.

There's so much more to do to ensure that every child with a neurodevelopmental disability receives the support they need to thrive. We need to do more to narrow the gap between scientific solutions and parents who are struggling in isolation.

Imagine the loss to children — and to all of us — if ground-breaking science and evidence-based solutions sit on a shelf instead of helping kids and families. Imagine families in crisis denied solutions that could help their child. That's what's at stake. And unless we can do more, the gap between science and parents will only grow. Kids will become teens and adults with unrealized potential.

That is why KBHN works tirelessly and singlemindedly to identify and fund the most promising scientific breakthroughs in kids' brain health. Working side by side with families, partners, funders, and our vast network of experts, we move innovation into practice. We help families and empower children. There are solutions and discoveries that science has unlocked but have not reached many of those who are supporting kids with neurodevelopmental disabilities. We can fix that. That's what we do.

By enabling early identification, intervention, and family support we can make kids' lives better. We can save money down the road in health care and social services. And most importantly, we can help children live their best lives.

Every child deserves this chance.



