



Jackson participates in equine therapy at Kindred Farm Rescue, a resource he has been able to access thanks to the FARP program.

Photo: Morro Creative

2020-21

IMPACT REPORT



kids | réseau pour
brain health | la santé du cerveau
network | des enfants



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Cover photo by Morro Creative.

EXECUTIVE MESSAGE

Kids Brain Health Network has a lot to celebrate.

At the start of 2020, we received an unprecedented three additional years of funding from the federal government's Networks of Centres of Excellence program (\$11.7M). The support and engagement from our partners was stronger than ever, our new research and training activities were underway, and KBHN was entering a new and exciting phase of its evolution.

Then came the pandemic. All in-person, face-to-face programs came to a halt. Children living with neurodevelopmental disabilities and their families suddenly lost crucial support systems. Front-line workers were put under incredible stress. Lockdowns stretched from weeks to months.

Despite the chaos and uncertainty, KBHN found a way forward. Our researchers pivoted quickly from in-person activities to online formats. In making these changes, unexpected benefits were revealed. Online programs were mitigating and in some cases eliminating geographical boundaries. Suddenly, programs like the Infant and Early Mental Health Hub for Training,

Resources, and Tools could reach thousands of individuals across Canada.

As the pandemic continued, we looked towards expanding our connections to community partners, and collaborating with new organizations. That's when KBHN and Mitacs joined forces to fund a series of special internships. Interns could now partner with community organizations to help them better understand COVID-19-related challenges and to develop necessary and inclusive solutions.

Together with its researchers and partners, KBHN demonstrated its resilience by adapting programs, learning new paths, and overcoming uncertainty. We are grateful for the effort made by staff, researchers, trainees, partners, communities, and most especially by the children living with neurodevelopmental disabilities and their families and caregivers, who have worked so hard during such challenging times. We are proud of our progress, and we look forward to the next three years with renewed commitment and determination.

VISION & MISSION



The Problem

In Canada, more than 400,000 children and youth under the age of 14 are living with a neurodevelopmental disability.

The Solution

There are no cures, only treatment. Earlier identification, earlier intervention and increased family support will reduce the impact of these disabilities on their daily lives.

Our Vision

All children living with neuro-developmental disabilities enjoy a good quality of life, inclusion in all aspects of society and reach their full potential.

Our Mission

Through catalyzing collective action across sectors, KBHN ensures optimal care and better outcomes for children with neurodevelopmental disabilities and their families.

Ultimately, KBHN bridges the gap between science and families. No other organization in Canada does what we do.

OUR IMPACT

In the words of parents



[Better Nights, Better Days] was a game changer for our child. Night and day, the difference it made! We were at our wits' end, fighting constantly with our child and ourselves due to sleep deprivation; our child only slept two hours out of 24 ... She now sleeps 10.5 hours a night and is a happy kid in the day. We can't speak more highly of the program and are constantly recommending it to parents in need."

A PARENT OF A THREE-YEAR-OLD DAUGHTER



It is so challenging raising a child with ASD ... [The Social ABCs] has helped me find hope that our son can perhaps speak one day and has given me ways to have fun with him and develop so many language opportunities that did not exist before. I find him a happier boy who shares lots of positive emotions with me."

A PARENT WHO PARTICIPATED IN THE SOCIAL ABCs INITIATIVE



[The Fetal Alcohol Resource Program] 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 NINE-YEAR-OLD DAUGHTER WITH FASD

KBHN BY THE NUMBERS



A PORTRAIT OF THE NETWORK 2020-21



41 network-funded investigators, plus **183** additional researchers and collaborators affiliated with network projects



3,197 front-line service-delivery personnel trained via network projects



37 family members and **28** researchers trained in Family Engagement in Research



209 highly qualified personnel (research trainees)



273 project partners



15,007 stakeholders engaged

KEY OUTPUTS 2020-21

25 projects and funded initiatives

43 research publications

128 stakeholder-engagement events

11 copyrights, trademarks, or intellectual properties

60 academic-training events

830 families receiving support in navigating services via network projects

FUNDING SOURCES 2020-21

* in millions of dollars



- **\$4** Networks of Centres of Excellence (NCE) funding
- **\$2.1** Partner contributions (cash)
- **\$2.2** Partner contributions (in kind)
- **\$0.2** KBHN Foundation

FUNDING SOURCES 2010-21

* in millions of dollars



- **\$47.07** from Networks of Centres of Excellence (NCE) (as of March 31, 2021)
- **\$39.31** Partner contributions



THREE FOCUS AREAS

Kids Brain Health Network is focused on proven solutions in three key areas.

Early identification

Too often, children with neurodevelopmental disabilities are not identified early enough. By reaching a child at the earliest possible age, we can have the greatest impact on their development. KBHN-funded research is breaking down barriers so children with these disabilities can be identified sooner.

Early intervention and effective treatment

Effective treatments need to be accessible in all parts of the country and to children of diverse cultures. KBHN is working at the cutting edge of treatment, to ensure all children and families can use these interventions anywhere and at any time.

Family support

Families raising children with neurodevelopmental disabilities face challenges that affect almost all aspects of their lives. Research funded by KBHN is identifying the most effective strategies to support parents and caregivers, reduce stress, improve communication, and increase family access to resources.



EARLY-IDENTIFICATION PROJECTS

FASD Epigenetic Screening Tool — Every year, hundreds of children are diagnosed with Fetal Alcohol Spectrum Disorder (FASD). This disability affects memory, cognition, and every facet of a child's life, making early identification critical. A team at the University of Manitoba has developed an assessment tool to do just that.

The test is a cheek swab, which identifies changes that happen to a gene after prenatal alcohol exposure. It's called the *FASD Code*, and it's a quick, effective, and cost-friendly method that's on its way to being implemented in four remote First Nations communities and the FASD clinic in Manitoba. Eventually, the team wants every community and clinic across Canada to be able to implement this tool on their own.

Principal investigators:
Geoff Hicks,
University of Manitoba
Brenda Elias,
University of Manitoba
Paul Pavlidis,
University of British Columbia

Infant and Early Mental Health Hub (IEMH) for Training, Resources, and Tools — Mental health is crucial for people of all ages, including children. The project, which was developed in consultation with First Nations communities across Canada, provides a culturally informed way of supporting infant and early mental health. The IEMH is delivered through both online and in-person learning. It even includes intensive coaching on how to find and navigate different mental-health services for children under the age of six. The hub, which has been accessed by more than 5,000 individuals across Canada, ultimately acts as a one-stop shop for practitioners to access information and resources on infant and early mental health.

Principal investigators:
James Reynolds,
Queen's University
Chaya Kulkarni,
Hospital for Sick Children

EARLY-INTERVENTION PROJECTS

eHealth for Neurodevelopmental Disabilities — Children with neurodevelopmental disabilities often struggle to both fall and stay asleep. This disruption to their sleep schedule affects their daytime routine and activities on an ongoing basis. Better Nights, Better Days for Children with Neurodevelopmental Disorders (BNBD-NDD) is an e-health intervention delivered through five online modules to help children achieve a peaceful night's rest.

Meanwhile, the ASSIST program (Accessible Strategies Supporting Inclusion for Students by Teachers) provides teachers with the tools to improve their knowledge and skills in working with students with neurodevelopmental disabilities.

Dino Island — Dino Island is a therapeutic game that improves attention, memory, and other skills in children with neurodevelopmental disabilities. It's also easy to use, which means parents and educators can support their children to play it at home or in the classroom. The game, which is hosted on a digital platform called *Teleroo*, has benefited more than 2,000 families. The team is now working towards implementing Dino Island across Canada.

KidsAction Coaching — Physical activity is beneficial to children living with neurodevelopmental disabilities, but community programs are often not designed with them in mind. KidsAction Coaching is building on existing community-based physical-activity programs across the country to ensure these children have access to these programs. When the pandemic hit, the team began to develop a website and pivot to online delivery of coach- and family-training modules.

Principal investigators:
Penny Corkum, Dalhousie University & IWK Health Centre
Shelly Weiss, University of Toronto & The Hospital for Sick Children



Principal investigators:
Sarah J. Macoun,
University of Victoria
Kimberly A. Kerns,
University of Victoria

Principal investigator:
Jean-Paul Collet,
University of British Columbia



Social ABCs — Social ABCs is a program for toddlers ages 12 to 36 months with diagnosed or suspected autism and those showing signs of delayed social communication. Trained coaches work with parents in-person or online, teaching them strategies for helping their toddlers communicate and interact socially. This KBHN-funded team is supporting efforts to create a training hub so service providers across the country can administer the intervention themselves.

Principal investigator:
Jessica Brian,
University of Toronto and
Holland Bloorview Kids
Rehabilitation Hospital



FAMILY-SUPPORT PROJECTS

Fetal Alcohol Resource Program — For families with children struggling with Fetal Alcohol Spectrum Disorder (FASD), identifying supports can be exasperating. The Fetal Alcohol Resource Program (FARP) is a community partnership focused on playing a navigator role. As such, it connects individuals and families to existing supports and services in their community. The team also offers professional consultations and customized workshops to help people better understand FASD.

Principal investigator:
James Reynolds,
Queen's University



The program currently supports families in Ottawa, Prescott Russell, and Stormont, Dundas, and Glengarry. The FARP team established a community of practice for all the Ontario Provincial FASD workers and launched nine virtual support groups for caregivers, children, youth, and adults impacted by FASD. The team also hosted a virtual FASD symposium and launched monthly bilingual FASD webinars, with more than 1,000 individuals accessing training through the program.

Integrated Navigational Support for Families of Children with Neurodevelopmental Disabilities — When a child receives a diagnosis, families are often unsure who to turn to or what steps to take. The Integrated Navigational Support for Families of Children with Neurodevelopmental Disabilities project is working with partners across Canada to ensure families get the help they need to navigate complex systems. The program has established three sites in British Columbia, Alberta, and the Yukon and is intended to act as a blueprint for other cities to adapt and adjust to address local needs.

Principal investigators:
David Nicholas,
University of Calgary
Lucyna Lach,
McGill University

Over 900 families in BC have managed seamless access to supports. In Alberta, a new database has been developed, which contains over 2,300 resources and more than 900 service organizations. The team also trained more than 200 navigators across the province. In the Yukon, families in rural and remote communities have received various support and intervention plans with the assistance of a Navigation Coordinator.



Social ABCs coach Sara Daoud works with Jina and her daughter Mimi who is autistic. Photo: Morro Creative.

THE SOCIAL ABCs

Mimi's Story

Mimi was diagnosed with autism at the age of two. At the time, Mimi had very few communication skills. She didn't respond to her name or look up when someone entered a room, and days would go by with her barely making a sound.

Shortly after, she started the Social ABCs program, a KBHN-funded program run out of Holland Bloorview Kids Rehabilitation Hospital in Ontario. The program is geared towards toddlers showing social communication challenges and those with suspected or diagnosed with autism.

"I was worried because at first, the goals of the program quite frankly seemed like impossibilities for Mimi," says her mother, Jina.

The Social ABCs is a parent-mediated intervention, where trained coaches work directly with parents in their homes or online. It is led by psychologist Dr. Jessica Brian, who co-developed the program alongside a psychologist, Dr. Susan Bryson. Coaches teach

parents strategies to help their toddlers communicate and interact socially.

Early in the program, Jina started to see changes in Mimi and in herself. About six weeks in, Mimi started walking for the first time. Despite walking not being a goal of the program, there are often cascading effects in developmental milestones when a child's brain becomes stimulated and when they start understanding motivation and attention.

"Social ABCs has had a huge impact on our entire family, grandparents included, on the way we parent Mimi," says Jina. "When you get this diagnosis, you're thrown into a deep ocean of trying to navigate supports with no assistance. For us, Social ABCs was this community of support, with people versed in autism who at the same time truly celebrated Mimi for who she is."

 [WATCH TO LEARN MORE](#)

BETTER DAYS BETTER NIGHTS

David's Story

For 10-year-old David, going to sleep was no easy task. According to his father Ben, David struggled with falling asleep and even when he managed to, he never woke up well-rested.

When David was diagnosed with attention-deficit/hyperactivity disorder (ADHD), he was referred to a study that was evaluating a new online health program called Better Nights, Better Days for Children with Neurodevelopmental Disorders (BNBD-NDD). It is led by child psychologist Dr. Penny Corkum and neurologist Dr. Shelly Weiss.

The goal of the program is simple: help children living with neurodevelopmental disabilities sleep better. It is designed specifically for children between the ages of 4 to 12 years old who have been diagnosed with ADHD, cerebral palsy, autism spectrum disorder or fetal alcohol spectrum disorder.

BNBD-NDD is self-guided and delivered online in five modules. Each module targets different aspects of sleep such as healthy sleep practices, settling to sleep, and going back to sleep. There is a great need for this type of program, as research suggests more than 85 per cent of children with a brain-based disability will struggle with sleep.

When the program was suggested to him, Ben says his family had reached a crisis point. His son's inability to fall asleep or stay asleep affected most aspects of his life. Over the course of 10 weeks, the duo sat down together every night and worked through the modules. For both Ben and David, who is now 12 years old, the program has been a game-changer.

“When your child is struggling, you worry terribly, and you feel like you're failing as a parent,” says Ben. “Better Nights, Better Days made a big difference in our lives and I'm a firm believer that this is a very helpful intervention.”



IMPLEMENTATION READINESS PROJECTS

In 2020, KBHN launched a pipeline of projects that are ready for implementation on a larger scale.

Working directly with stakeholders on the ground is key to moving science into practice, so researchers were thrilled to see enormous engagement from caregivers, clinical staff, and community workers.

Initially, COVID-19 seemed like a threat to this engagement, but many of KBHN's projects managed to pivot to a virtual model, which actually allowed them to reach even more people than expected. Going forward, the network will continue to prioritize implementing widescale, lasting benefits for children and families and to measure its success in these terms.





Client-Oriented Mapping for Point of Care Access to Supports and Services (COMPASS) — After a child receives an FASD diagnosis, families sometimes feel confused, frustrated, and overwhelmed as to what to do next. The COMPASS program uses an algorithm to generate recommendations, pathways, and connections that are simple, concise, and understandable. COMPASS is an unparalleled opportunity to put the power back in the hands of families.

Principal investigator:
Jocelynn Cook,
Society for Obstetricians &
Gynecologists of Canada

Mathematics Interactive Learning Experience (MILE) — Math is challenging for many children, especially those with neurodevelopmental disabilities. The MILE program offers individualized tutoring to improve math skills and build confidence. The program has been so successful that it is now being adapted for classroom use for all children. implementing Dino Island across Canada.

Principal investigators:
Carmen Rasmussen,
University of Alberta
Jacqueline Pei,
University of Alberta

Early Detection and Intervention Toolkit for Cerebral Palsy (EDIT-CP) — For cerebral palsy (CP), children need to be diagnosed as early as possible. The EDIT-CP project is finding ways to help therapists and early interventionists diagnose and treat CP sooner. The toolkit not only shares assessment guidelines but effective recommendations for primary-care physicians.

Principal investigators:
Darcy Fehlings,
Bloorview Rehabilitation
Sciences Institute
Annette Majnemer,
Research Institute of the McGill
University Health Centre

Secret Agent Society — Kids with autism commonly struggle to regulate their emotions and handle the day-to-day stressors in their lives. This leads to an increased risk of depression, anxiety disorders and anger issues. Secret Agent Society is designed to help school-aged children with autism crack the code by teaching them to recognize emotions and express them appropriately.

Principal investigator:
Jonathan Weiss,
York University

Intelligent Solutions for Sound Sensitivity in Children with Neurodevelopmental Disorders — Many children living with autism are hypersensitive to certain sounds. Now, there's a device that selectively filters out the specific noises that cause distress. This device will help kids with autism feel more comfortable in their daily lives and encourage participation in school and recreational activities.

Principal investigators:
Elina Birmingham,
Simon Fraser University
Siamak Arzanpour,
Simon Fraser University

TRAINING

Training the next generation of neurodevelopmental professionals is a top priority for KBHN.

In 2020-2021, we embedded over 200 individuals in project teams and with community partners, providing trainees with first-hand experience in patient-oriented and community-driven approaches. Over the life of the Network, more than 600 individual trainees have benefited from the program. Here are some of the highlights.



The Policy Advisory and Research Training (PART) Committee helps design and plan trainee opportunities for KBHN. PART gives trainees an opportunity for career development in policy, research, and implementation sciences. They share research and professional insights, advise on KBHN-trainee needs, and collaborate to develop programs and events. They also took a larger role in developing 2020 Annual (Virtual) Conference training events. In February 2021, 14 trainees from across Canada were elected as PART members.

The Family Engagement in Research (FER) Certificate Program was developed in partnership with CanChild and McMaster University Continuing Education. Launched in 2018, the FER course allows researchers and families to co-learn how to effectively partner together throughout the research process. To date, there are 224 graduates (107 family members; 117 researchers) of the FER course from eight cohorts (Fall 2018 – Winter 2022) from across Canada and the world. A key component of the FER Course is a group project to create a knowledge-translation (KT) tool about a topic relevant to family engagement in research. To date, students have created over 70 KT tools that include infographics, blogs, videos, presentations, podcasts, etc. All KT tools are [available on the KBHN website](#).

The CASDA-KBHN Policy Practicum Fellowships were created in partnership with the Canadian Autism Spectrum Disorder Alliance (CASDA; now called Autism Alliance of Canada). The goal is to give trainees experience working with policy and decision-makers in government and community organizations. Three cohorts of Policy Fellows have been awarded: five fellowships in 2020, six fellowships in 2021, and three new fellowships in 2022.

In 2021, the award included a \$2,000 stipend for each awardee and support to present at the CASDA and KBHN annual conferences. For 2022, the stipend has been increased to \$4,000 and awardees will once again receive support to make presentations at both annual conferences.

Over a six-month fellowship, the 2020 cohort co-produced and published a policy-brief compendium representing the five pillars identified in the Blueprint for a National Autism Strategy framework. The 2021 cohort of fellows led extensive stakeholder consultations and co-produced three policy briefs supporting the stakeholder-consultation work informing the development of the National Autism Strategy.

KBHN-Mitacs Research Awards are internships jointly funded by KBHN, Mitacs, and host-community organizations. They provide opportunities to support projects that focus on enhancing services and support for children with neurodevelopmental disabilities and their families across Canada. In 2020, nine internships were awarded for a total of \$140,000. The interns worked with seven community-based organizations to develop necessary, inclusive, evidence-based solutions to better understand COVID-19-related challenges faced by children with neurodevelopmental disabilities and their families. Two projects we'd like to highlight are:

- a. Maude Champagne (Queen's University), in conjunction with ABLE2, worked to better understand the social-support needs of families raising children and youth living with Fetal Alcohol Spectrum Disorder (FASD) and how these needs were impacted during the pandemic.
- b. Vanessa Fong (Simon Fraser University) partnered with Autism Community Training (ACT) for a survey of caregivers titled "Understanding the impact of COVID-19 on families of autistic children."

NEW AND EMERGING WAYS OF CONNECTION



The 2020 KBHN Virtual Conference

Due to the COVID-19 pandemic, KBHN moved its annual conference online. The theme was chosen as “New and Emerging Ways of Connection.” It focused on the innovative solutions that our community uses to break down barriers to access to care and resources for families.

The impact of the conference was palpable. Not only did attendance remain high, with 293 participants, but our discussions were also stimulating. We did this by breaking down the four-day event into themes that highlighted challenges, innovations, and our community’s ever-growing commitment to progress.

The first day stressed the vital role of accessing services in a COVID-19 world. The second day underscored emerging ways of delivering treatments. The third day emphasized the importance of moving online to expand our reach and increase access. And the final day highlighted the changing dynamics of policy and decision-making in a global pandemic. In total, the conference featured nearly 50 posters and over 100 speakers, including eight short research summaries (“lightning talks”) from trainees.

Award-winning CBC host Brian Goldman emceed the event. His commentary, which helped to illuminate links between the insights of different presenters, was informed by not only his skill as a medical-science communicator but also his lived experience as a father of a young adult with FASD.

The Fraser Mustard Lecture, dedicated to advancing knowledge about the importance of early child

development, is a highlight of each year’s conference. This year’s awardee was Dr. Cindy Blackstock, an officer of the Order of Canada and the executive director of the First Nations Child & Family Caring Society of Canada. She spoke passionately about the systemic barriers and inequities that Indigenous children face within Canada and the changes that could rectify this situation.







We also welcomed Carla Qualtrough, the Minister of Employment, Workforce Development and Disability Inclusion, Conservative MP Mike Lake and three independent senators: Rosemary Moodie, Jim Munson, and Colin Deacon. All are fervent advocates committed to inclusion for children and youth with disabilities.

Our theme of connecting in new ways was well-represented throughout the conference’s run — not only in the content of its presentations but also in the way that the organizers delivered it. They optimised networking using an online platform that enabled breakout sessions, exhibit booths, poster sessions, and Meet the Experts sessions. The Policy Advisory Research Training Committee (PART), in addition to organizing trainee-related events, served as ambassadors assisting and training conference delegates on the virtual-networking platform.







As a result, thoughtful collaborations and innovations were honoured and necessary connections were made between both people and ideas. KBHN intends to continue this trend as we look toward the future. Connecting and teaming up is how we ensure success.

FINANCIALS

Receipts

Contributions from Networks of Centres of Excellence (NCE)	\$2,652,931	
Contributions from National Sciences and Engineering Research Council (NSERC)	\$365,935	
Contributions from Kids Brain Health Foundation (KBHF)	\$281,846	
Contributions from Institute for Health System Transformation and Sustainability (IHSTS)	\$153,120	
Conference registration fees and other support	\$55,065	
Amortization of deferred capital contributions	\$2,908	
	\$3,502,805	

Expenditures

Research, Knowledge mobilization and Training	\$2,306,684	
Operating and Administration	\$612,091	
Travel, meetings and networking	\$143,006	
Professional and consulting fees	\$100,860	
Communications	\$85,980	
Insurance	\$10,602	
	\$3,259,223	

[Audited Statements >](#)

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Kids Brain Health Network would like to express our deepest appreciation to our 2020-2021 Board Members for their unwavering support.



KBHN delivers real value to the neurodevelopmental research community in Canada and improves the lives of children living with neurodevelopmental disabilities.”

DAVID KUIK, BOARD CHAIR



Next Steps for KBHN

The impact of COVID-19 and the effects of a global pandemic are still reverberating. Although there are many reasons to be hopeful, there is still so much more we can accomplish together.

Moving forward, we recognize the critical importance of supporting children with NDDs in post-pandemic recovery plans. We need to prioritize the families, the frontline healthcare workers, the researchers, and the trainees who have struggled to overcome barriers.

KBHN plays a key role in finding and funding the most promising research. We utilize implementation science — best practices with known results — to ensure that our interventions are widely available and that barriers to access are overcome.

With the support of the Canadian government, our host institution — Simon Fraser University (SFU) and the Office of the Vice President of Research, SFU — and our network of outstanding partners, KBHN will concentrate on three integrated and complementary objectives. We need to improve outcomes for vulnerable children and families, accelerate the impact of research innovations, and strengthen the research ecosystem.

Our next steps are to continue engaging with policymakers, government, and community leaders to put the needs of children with neurodevelopmental disabilities front and centre. Together, we can help all kids live their best lives and reach their full potential.

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