



2021-22

IMPACT REPORT



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

EXECUTIVE MESSAGE



Nicky Lewis
Chief Executive Officer



Dr. James Reynolds
Chief Scientific Officer

As Kids Brain Health Network (KBHN) entered its twelfth year, families affected by neurodevelopmental disorders (NDDs) were facing even more challenges than usual because of pandemic-related service interruptions. In fact, research conducted by our trainees in partnership with frontline organizations revealed that a significant number of families were in crisis, facing breakdown.

As restrictions eased and Canada began planning for pandemic recovery, we championed Canada's hundreds of thousands of children with NDDs and their caregivers, who deserve solutions and supports they can count on in all circumstances. We also continued researching flexible, sustainable ways to help them live their best lives, knowing that these innovations need to enter into practice—and remain there—to have a lasting impact.

To this end, many of our research teams focused on spreading solutions across the country via our growing, multijurisdictional network of partners. They have also been removing barriers and helping new practitioners to implement their findings, even under challenging conditions. For example, researchers are making evidence-based programs available online, and testing versions that call for fewer resources.

To ensure that such impactful research continues, training the next generation of neurodevelopmental professionals and researchers is a top priority for KBHN. In 2021-2022, project teams engaged over 200 trainees and community stakeholders with research and implementation activities, providing them with experiential learning opportunities.

Meanwhile, our Board of Directors and the executive team have been focusing on the sustainability of KBHN's mission after our third and final cycle of funding under the federal NCE program. We have strategized about financing the continuation of our work via government funding initiatives, philanthropy and commercialization. Promising steps have been made on all three fronts.

KBHN is making an important impact, but there is still more work to do. Our team, network members and partners are as dedicated as ever to advancing evidence-based solutions and supporting their implementation so they can reach and benefit as many kids as possible.

Thank you to all who are contributing to this progress with their skills, expertise, lived experience, funds or efforts

AN UPDATE FROM OUR FOUNDATION

With an eye to sustaining KBHN's vital work, the registered charity Kids Brain Health Foundation focused on building its infrastructure this year, while also raising money for meaningful initiatives. Notably, we received generous multi-year philanthropic support from the Azrieli Foundation/la Fondation Azrieli and an anonymous donor. These contributions supported the Integrated Navigational Support Program, a cross-Canada initiative that is improving regional service navigation so that families of children with neurodevelopmental disabilities can find and access the supports they need. You can read more about it [here](#).

To lay the groundwork for further growth, a working group comprised of staff and foundation board members developed our value proposition, and our governmental and philanthropic cases for support.

Moving forward, the foundation will ramp up its efforts to engage community leaders in supporting our efforts so that kids with neurodevelopmental disabilities can thrive. We welcome you to join them.



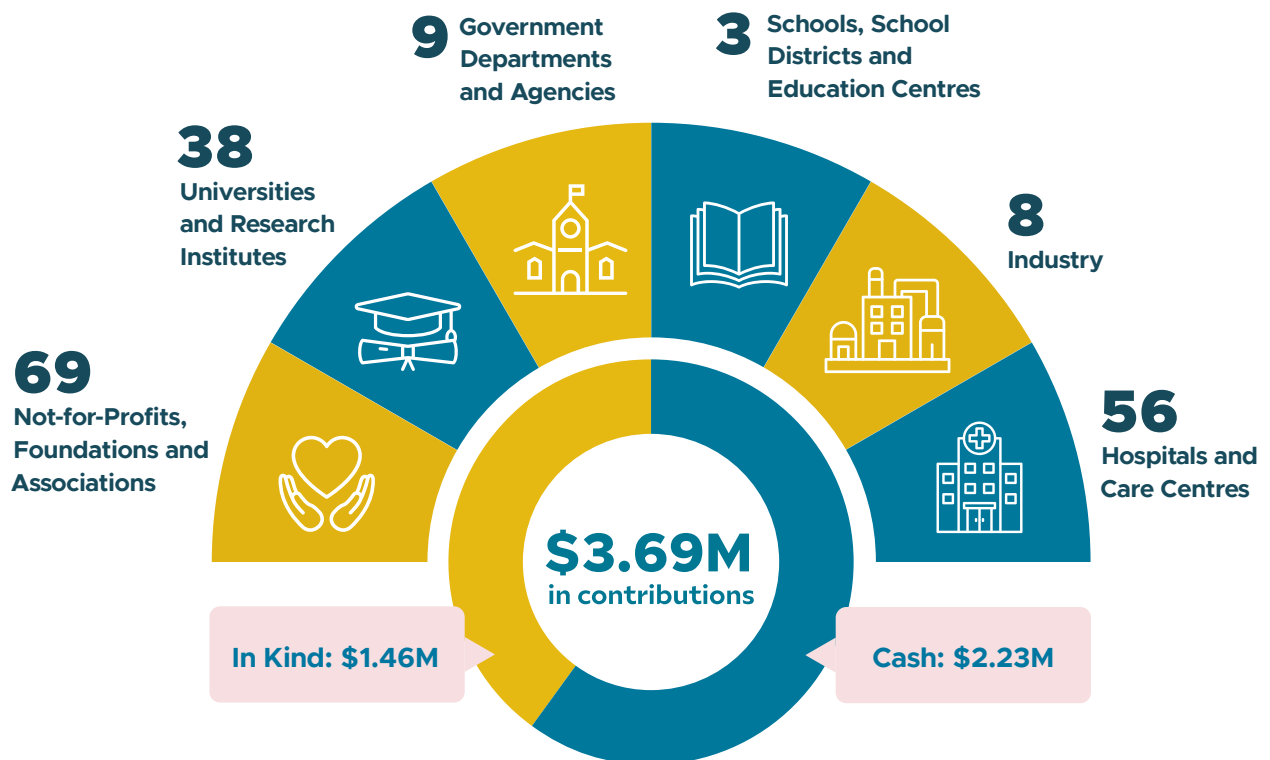
Sheila Laredo
Chair, Kids Brain
Health Foundation

THE YEAR IN NUMBERS

PARTNERS IN SUSTAINABLE IMPLEMENTATION

Our partners are the two-way bridge between scientific discoveries and the families who need them most.

Their investment of time, funding and expertise show their dedication to supporting our research and putting it into practice.



BUILDING LONG-TERM CAPACITY TO SUPPORT COMMUNITIES AND FAMILIES

By training and engaging promising young researchers, persons with lived experience, passionate frontline workers and other stakeholders, we contribute to a robust ecosystem of knowledge exchange and skills development. Here are some of the people we engaged this year.



61 researchers and family members graduated from the Families Engaged in Research (FER) course

The FER course helps researchers and families learn to partner together effectively throughout the research process.



222 highly qualified personnel accessed training and experience through Network research projects and internships.

Our national training program prepares the next generation of professionals to foster better outcomes for children with neurodevelopmental disabilities and their families.



5,790 frontline service delivery personnel participated in training workshops and courses delivered by KBHN researchers.

KBHN is committed to ensuring that children with NDDs and their families are served and supported well by doctors, therapists, teachers, social workers and others.



150 associate trainees took part in Network training events.

A sub-committee of trainees organized webinars to promote the professional development of all.



More than 16,500 stakeholders engaged with Network-sponsored events across Canada.

From the 2022 Infant and Early Mental Health Lecture Series to the Fifth Annual Eastern Ontario FASD Symposium, KBHN-funded research teams hosted over 750 events this fiscal year.



226 participants & 53 speakers exchanged knowledge at KBHN's annual conference.

ABOUT KIDS BRAIN HEALTH NETWORK



Children and youth with a neurodevelopmental disability such as autism, cerebral palsy, FASD, among others, comprise 75 % of young people in Canada. At least 90% of these kids will face limitations that impact quality of life—from mental health challenges to poorer health and socioeconomic outcomes

While there continue to be advancements in the science of children's brain health, these discoveries often don't make it to the children and families who need them. By working with well-positioned partners, Kids Brain Health Network (KBHN) bridges gaps between science and families, connecting Canada's leading researchers with the children who can benefit the most from their work.

Our Vision

All children living with neurodevelopmental 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.

THREE FOCUS AREAS

Early identification

The sooner a neurodevelopmental disability is identified, the sooner treatment can begin. Too often, children with NDDs are not identified during the critical early periods of brain development when interventions have the greatest impact. Research funded by KBHN is breaking down barriers to assessment and pushing diagnostic capacity into infancy.

Early intervention and effective treatment

Childhood interventions for neurodevelopmental disabilities open opportunities for very real progress, which means they must be accessible in all parts of the country and to diverse cultural and linguistic groups. KBHN is working at the cutting edge of treatment, to ensure that all families can benefit early on.

Family support

Families raising children with neurodevelopmental disabilities face challenges that affect most aspects of their lives. Our research is identifying the most effective solutions to help families reduce stress and give their children what they need to live their best lives.



Kids Brain Health Network is taking promising steps through government funding and commercialization, to create enduring improvements for children with neurodevelopmental disabilities, their caregivers and families.

DAVID KUIK, BOARD CHAIR FROM SEPTEMBER 2020-SEPTEMBER 2021



Through hard work, commitment and dedication to our vision, KBHN engages the research community, builds capacity for frontline community agencies, and scales supports and programs for children and families.”

GEOFF PRADELLA, BOARD CHAIR BEGINNING SEPTEMBER 2021

In the Words of Families and Partners



This is a fantastic tool for us to use when supporting families! I feel so lucky to work for an agency that is so forward thinking, and we get to start implementing this right away.”

FRONTLINE PRACTITIONER WHO PARTICIPATED IN THE F-WORDS FOUNDATIONS COURSE



It allowed me to recognize my grandchild’s growth and gave me insight into what I could help with to improve my grandchild’s progress.”

GRANDPARENT WHO HELPED TO DELIVER NURTURING THE SEED, A DEVELOPMENTAL-SUPPORT PROGRAM WITH AN INDIGENOUS LENS



Social ABCs has had a huge impact on our entire family, grandparents included, on the way we parent Mimi... For us, it was this community of support, with people versed in autism who at the same time truly celebrated Mimi for who she is.”

PARENT OF A TODDLER WITH ASD



[My child] is more confident in social situations. Many strategies have helped, and she made new friends.”

PARENT OF A CHILD WITH ASD WHO PARTICIPATED IN THE SECRET AGENT SOCIETY INTERVENTION



I work in public health and see families and new babies often. I found this a very useful resource that I will definitely be drawing from to improve my practice.”

FRONTLINE PRACTITIONER WHO TOOK TRAINING THROUGH THE INFANT AND EARLY MENTAL HEALTH HUB





OUR SOLUTIONS

Putting Science to Work for Families

In its twelfth year, Kids Brain Health Network expanded its research portfolio while keeping a firm emphasis on the large-scale implementation of our research outputs. Examples of these outputs include:

- Programs and interventions that make a difference for kids' development and the whole family's well-being
- Apps and devices that help children strengthen key skills or enjoy a better quality of life
- Policy documents for the people who make decisions that affect children and their families
- Training packages and practice guidelines for researchers, parents and the frontline professionals who support children and their families

Five new projects joined the network in 2021-2022, bringing with them partners who are ready and willing to take up its evidence-based solutions. Meanwhile, many of KBHN's mature research projects are leading implementation studies, which discover the factors and methods that make these solutions more likely to spread, get adopted and make a lasting impact.



292+ RESEARCHERS & 222 TRAINEES

worked on KBHN's research projects this year



500+ CHILDREN, FAMILY MEMBERS & FRONTLINE WORKERS

participated in KBHN-affiliated studies in 2021-2022

EARLY-IDENTIFICATION PROJECTS



Early Detection and Intervention Toolkit for Cerebral Palsy (EDIT-CP)

Principal investigators:

Dr. Darcy Fehlings, Holland Bloorview Kids Rehabilitation Hospital

Dr. Annette Majnemer, McGill University

Dr. Tatiana Ogourtsova, McGill University

This year, EDIT-CP helped 5 rehabilitation centres across Ontario to establish programming for infants with cerebral palsy

What it is: According to international guidelines, doctors should ideally diagnose cerebral palsy (CP) before a baby's first birthday. This way, the child can access early interventions that will help them reach their fullest potential for movement and function. However, the average age for a CP diagnosis in Canada is 18.9 months. To address this shortcoming, EDIT-CP is implementing early-detection tools in neonatal follow-up programs—which monitor infants who are at high risk of developmental conditions—and with family doctors, who see low-risk babies. The team is also building capacity for early-intervention programming with a focus on Baby CIMT, a treatment that is often helpful for a common kind of CP.

Highlights of 2021-2022: So far, the team has worked with five neonatal follow-up clinics in Ontario to implement an early-detection tool called the Hammersmith Infant Neurological Examination (HINE). For infants who come through family doctor's offices, they've arranged to add crucial information related to signs of CP to the Rourke Baby Record, a guide many physicians use at routine baby checkups. They also developed easy-to-follow illustrations of these signs, and an online resource that answers FAQs and summarizes the evidence for various early interventions.

To improve the availability of such treatments, the team helped rehabilitation centres in Ontario to establish programs in Baby CIMT. Building upon this provincial success, they now plan to expand their efforts to the national level



FASD Code

Principal Investigators:

Dr. Geoff Hicks, University of Manitoba

Dr. Brenda Elias, University of Manitoba

Dr. Paul Pavlidis, University of British Columbia

What It Is: FASD Code involves a cheek swab that tests for changes that may occur throughout the genome after prenatal alcohol exposure. This makes it a simple, cost-effective way to identify young children who may develop fetal alcohol syndrome disorder. Given that children are usually school-aged before they get a diagnosis, FASD Code could allow families and service providers to understand and address a child's challenges sooner.

Next Steps: For a study co-designed and led by the Cree Nation Tribal Health Centre, community clinics in several remote First Nations communities will implement FASD Code and help to evaluate it. The Manitoba FASD Centre will also participate in implementation research..



The Infant and Early Mental Health Hub for Training, Resources and Tools (IEMH Hub)

Principal investigators:

Dr. James Reynolds, Queen's University

Dr. Chaya Kulkarni, The Hospital for Sick Children

Over 12,000 users have an account with the IEMH Hub's learning-management system.

What it is: Mental health is crucial for people of all ages, and especially young children, because their brain development is the most active by far. The Infant and Early Mental Health Hub aims to improve young kids' socioemotional development by enhancing the skills and knowledge of the practitioners who work with them, including social workers, early-childhood educators, home visitors and medical staff.

The IEMH Hub's many resources include a developmental-screening training module that could improve practitioners' ability to detect children with developmental delays, and Nurturing the Seed, a culturally sensitive developmental-support program created in consultation with Indigenous communities across Canada.

Highlights of 2021-2022: The project team, known as Infant and Early Mental Health Promotion (IEMHP), continued to populate the IEMH Hub with evidence-based resources this year, including their coaching model, Coaching Connect. So far, 10 coaching sessions have been delivered to 105 participants.

Although in-person learning remains an option, all trainings are now offered online. A learning management system that provides centralized access to trainings launched in September 2021. More than 12,000 people have signed up to it so far.

The team also established over 20 new partnerships and contracts. For example, the Ontario Association of Children's Aid Societies funded access to the IEMHP's 2022 Lecture Series for all 50 child-welfare agencies in Ontario. They also contracted IEMHP to develop a series of resources specifically for foster, kin or customary caregivers. In the meantime, seven new communities and agencies adopted Nurturing the Seed, which is now available in both English and French.

EARLY INTERVENTION AND EFFECTIVE TREATMENT PROJECTS



Babbly

Principal investigators:

Dr. Anna McCormick, Children's Hospital of Eastern Ontario
Dr. Christopher Fennell, University of Ottawa

What it is: The Babbly app uses artificial intelligence to analyze recordings of a child's voice and to assess their speech and language development. It also provides targeted speech-promoting activity suggestions. Designed to be fun and easy to fit into everyday routines, these activities give parents the chance to participate in their child's learning.

Next Steps: KBHN's research will focus on whether Babbly could help families who are waiting for speech and language evaluation and services, which can take up to a year to access in Canada.

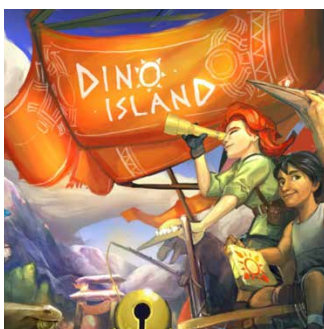


BCi-Move

Principal Investigator: Dr. Adam Kirton, University of Calgary

What It Is: Brain-computer interfaces (BCIs) recognize changes in thought patterns through a non-invasive headset and transmit those signals to electronic devices. A child could think the word "go," for example, to move a scooter forward. The BCi-Move project aims to determine if children with severely limiting physical disabilities can use this cutting-edge technology to achieve personalized mobility goals.

Next Steps: Over 12 training sessions, participating kids will explore a power-mobility training device through play-based activities while researchers monitor their skill progress, their brain activity and their level of satisfaction with the technology. These findings will lay the groundwork for BCI power mobility camps, independent play and possibly even the use of electric wheelchairs in everyday life.



Dino Island

Principal Investigator: Dr. Sarah J. Macoun, University of Victoria

What It Is: Dino Island is a tablet-based game designed specifically for children with neurodevelopmental disabilities (NDDs). Studies in children with ASD and FASD have shown that it helps with attention, memory, self-regulation, emotional and behavioural control, self-confidence, the use of problem-solving strategies and academic performance. A companion website trains therapists, teachers or parents to support children in playing the game and applying the skills it strengthens to other areas of life.

Highlights of 2021-2022: New implementation sites joined the project this year, including Calgary Quest School, a specialized school for kids with disabilities, and the Mayo Clinic, which will be conducting a trial with children who've been treated with cranial radiation for brain tumours.

The team also began studying how Dino Island works in private homes, under the supervision of parents. Based on participant feedback, they've made some changes to the program that will make it easier for families to monitor their progress and keep themselves motivated.



eHealth for Neurodevelopmental Disabilities

Principal Investigators:

Dr. Penny Corkum, Dalhousie University

Dr. Shelly Weiss, University of Toronto

More than 100 new teachers learned about effectively supporting children with NDDs through the ASSIST program this year.

What it is: This project encompasses two online programs. The first addresses the fact that children with NDDs have an increased risk of struggling to fall and stay asleep. This sleep disruption can affect their ability to feel well and do their best during the day. Better Nights, Better Days for Children with Neurodevelopmental Disorders (BNBD-NDD) is an e-health intervention that helps parents to improve kids' insomnia.

ASSIST (Accessible Strategies Supporting Inclusion for Students by Teachers) helps teachers to support students with NDDs. This meets a crucial need: most mainstream classroom teachers report they don't have adequate training to work effectively with this group of kids, despite growing demands upon them to do so.

Implementation Highlights of 2021-2022: The team is working toward making their eHealth programs commercially available. They've submitted trademark applications and signed a licensing agreement for ASSIST with Velsoft Training Materials, a fast-growing Canadian software company. The contract dedicates 15 per cent of revenue to research and development so that the technology and content can be updated as needed. For example, the researchers created a new module about disruptive classroom behaviour this year, in response to teacher demand.

They are also conducting sustainability and implementation studies for both ASSIST and BNBD, to increase the likelihood that teachers and families will be able to access these programs, use them effectively, stick with them and reap rewards for years to come.



Intelligent Device for Sound Sensitivity

Principal Investigators:

Dr. Elina Birmingham, Simon Fraser University

Dr. Siamak Arzanpour, Simon Fraser University

What it is: Many children living with autism are hypersensitive to certain sounds. Schools' approaches for accommodating sound sensitivity include letting students wear earplugs or earmuffs or allowing them to take breaks in a quiet area. Because such strategies block or avoid all sounds indiscriminately, they interfere with the child's full participation in class and other activities. This team of researchers is developing a device that selectively filters or reduces specific noises that a child finds distressing (e.g., dogs barking, sirens, jackhammers) while allowing them to hear other sounds, such as the teacher's voice.

Highlights of 2021-2022: This year, the team developed a sound-filtration technique that can remove aversive sounds while preserving the intelligibility of speech, even in complex noisy conditions. They also created a visual user interface for the device, and an algorithm that will allow it to learn about new kinds of aversive sounds when users flag them. Only a few samples of these sounds are needed to help the device recognize them.



KidsAction Coaching

Principal Investigator: Dr. Jean-Paul Collet, University of British Columbia

What it is: Participating in sports and recreation brings a whole host of benefits to kids with NDDs, including the development of healthy lifestyle habits, self-esteem, self-control, physical abilities and social skills. However, community programs are often designed without them in mind.

KidsAction Coaching helps programs become more accessible to all. It's an approach that involves understanding each child's specific abilities, adapting activities as needed and highlighting progress. KidsAction Coaching also engages children's families: Coaches give parents a personalized list of activities they can practice with their child at home, along with access to instructions and videos.

Highlights of 2021-2022: The team developed a website to enable online delivery of training modules for organizations, coaches and families. It includes a bank with more than 140 activities for developing gross-motor skills at home, including 23 with an Indigenous focus and 60 for very young children.



The Math Interactive Learning Experience (MILE)

Principal Investigators:

Dr. Jacqueline Pei, University of Alberta

Dr. Carmen Rasmussen, University of Alberta

What It Is: Originally developed for children with fetal alcohol syndrome disorder, MILE is an evidence-based intervention geared toward building the underlying cognitive skills that are critical to math. Not only do math skills improve, but also behavioural functioning in the classroom. This creates a foundation for later success in math—and school more generally.

Highlights of 2021-2022: MILE was originally a tutoring program that relied on individual or small-group instruction, which can be a tall order for schools with limited resources. To make MILE less costly to adopt and to provide a more inclusive classroom experience, this research team adapted it for teachers to use with all the children in their class, including those with gaps in their understanding in math. They achieved this with support from a community of practice consisting of math experts, consultants and teachers. The next step is to pilot the adaptation in real classrooms.



Secret Agent Society

Principal Investigators:

Dr. Vivian Lee, Carleton University

Dr. Jonathan Weiss, York University

So far, 7 KBHN-partnered autism-service agencies have delivered Secret Agent Society to around 300 families.

What it is: Children with autism often have challenges with social skills and emotional regulation, which increases their risk of mental-health issues such as depression, anxiety disorders and behavioural challenges. The Secret Agent Society: Small Group Program (SAS:SG) digital software provides fun espionage-themed activities and tools including a digital board game, role playing and a computer game. It targets core areas of difficulty for kids with autism, such as developing desired friendships, working in teams and problem-solving. SAS:SG also helps children recognize emotions, express them in helpful ways and cope with challenging ones.

Highlights of 2021-2022: Previously, this team had shown that SAS:SG is efficacious under ideal conditions, in a tightly controlled experiment with expert facilitators at York University. This year and last, the researchers partnered with autism-service centres in the Toronto area to see whether it can be similarly helpful in real-world conditions. It turned out that participation in the program was feasible for families even during a pandemic, with a high attendance rate across all sessions. What's more, the children who completed the program tended to see improvements in their social and emotional skills, while parents and therapists reported being highly satisfied with it.



Social ABCs

Principal Investigator: Dr. Jessica Brian, University of Toronto

To date, over 500 families have been able to access the Social ABCs.

What it is: Social ABCs is a program for toddlers with diagnosed or suspected autism and those showing signs of delayed social communication. Given that evidence-based interventions for kids under age three have not been widely available, Social ABCs is filling a service gap at a key stage of brain development when kids may benefit the most. Trained coaches work with parents one-on-one or in a group setting, teaching them strategies for helping their toddlers to communicate and interact socially. A KBHN-funded team has been establishing the evidence base for the program and improving access to it across the country.

Highlights of 2021-2022: The team has set up a website to ensure people can learn about Social ABCs from a single reliable source, with information that is kept up-to-date.

In the hopes of making Social ABCs delivery more flexible, the researchers conducted a trial of a virtual version of the program's group-based model, to see if it can be as effective as the in-person version. Results were promising.

Seven new community-implementation sites joined the project during this year, one of which was a province-wide partnership with Prince Edward Island. Each site has one or two coaches who are receiving enhanced training so that they will be able to train other coaches going forward.

FAMILY SUPPORT PROJECTS



Acceptance and Commitment Training (ACT) for Family Caregivers

Principal Investigators:

Dr. Johanna Lake, Centre for Addiction and Mental Health

Dr. Yona Lunskey, Centre for Addiction and Mental Health

Dr. Kenneth Fung, University Health Network

What It Is: ACT is an intervention that helps people improve their mental well-being by accepting their thoughts and feelings—even those that are painful—and living an engaged, meaningful life aligned with their values. This research team has helped to develop ACT-based workshops that are co-led by clinicians and caregivers together. Caregivers of people with autism and fetal alcohol spectrum disorder (FASD) who've participated in these workshops have reported feeling less depressed, stressed and isolated.

Next Steps: The team has been training new facilitators across Canada to deliver ACT workshops, both in person and online. The researchers will investigate what factors make it easy or hard for clinicians and caregivers to work together in delivering the intervention, whether or not it enhances participants' mental health and resilience, and how it might need to be adapted as it spreads into new agencies and communities.



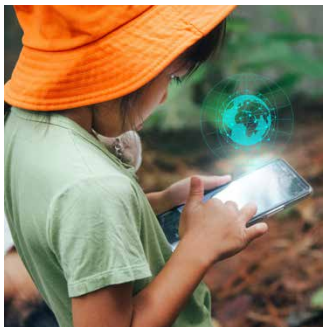
The Family Check-Up

Principal Investigators:

Dr. Teresa Bennett, McMaster University
Dr. Irene Drmic, McMaster Children's Hospital

What It Is: Research has shown that access to services, social connections and parenting skills can influence families' well-being in important ways. Despite this knowledge, Canadian autism services rarely ask about—or act upon—these known factors. The Family Check-Up program aims to change this reality. Parents first complete an assessment that helps the clinician to provide non-judgmental information about strengths and areas for improvement in parenting, as well as services in the community that could help the family. In addition, short sessions are available to help parents gain practical skills to address the specific challenges they're facing.

Next Steps: Studies have found that Family Check-Up often improves long-term child and caregiver mental health in families with non-autistic children, but we don't yet know if it can be delivered effectively within an autism-service setting. This research team is studying this question by helping to establish a Family Check-Up clinical team within the McMaster Children's Hospital Autism Program. They will study whether it reduces emotional and behavioural problems in autistic children and improves parent well-being. They will also learn about how best to implement it into other autism-service centres.



Client-Oriented Mapping for Point of Care Access to Supports and Services (FASD COMPASS)

Principal Investigators:

Dr. Jocelynn Cook, University of Ottawa
Dr. Jacqueline Pei, University of Alberta
Dr. Kaitlyn McLachlan, University of Guelph

What It Is: Every person with FASD has their own strengths and challenges. That means there's no one-size-fits-all pathway through the available supports and services. Instead, families have to figure out what makes the most sense given their child's needs, age, goals and context. Client-Oriented Mapping for Point of Care Access to Supports and Services (COMPASS) is a resource informed by nationwide data about the characteristics of individuals with FASD, their experiences, and the supports they've used at different stages of their lives (e.g.

academic coaching, mental-health services, social-skills training, etc.) COMPASS aims to apply past learnings to new patients, so that FASD clinics can give meaningful, evidence-based recommendations to families when their child gets a diagnosis.

Highlights of 2021-2022: Using the KBHN-supported National FASD database and interviews with four FASD-clinic partners about how they work with their clients, this research team created a COMPASS prototype that can now be implemented and evaluated.



Fetal Alcohol Resource Program (FARP)

Principal Investigators:

Dr. James Reynolds, Queen's University
Manon Kelso, ABLE2

*To date, FARP has trained **more than 4,850 people** working in sectors such as education, health, law enforcement and social services. The team has also responded to over **900 requests from families** for navigational and clinical support.*

What It Is: Now active in three Ontario regions, FARP began as a navigation service, helping to connect people living with FASD and their families to existing programs in their community. Now it also hosts support groups and provides families with FASD workers who can help them to get a diagnosis, understand the medical system, advocate for their children at school, and more.

In the wider community, FARP raises awareness of FASD and trains professionals from a variety of sectors (e.g. education, healthcare, mental health, criminal justice, child welfare and housing) about the disorder and how to improve the ways they serve people.

Highlights from 2021-2022: In September 2021, FARP organized an awareness walk in Ottawa that put a focus on people's lived experiences with FASD. Throughout the rest of the year, it hosted 149 support-group meetings for a total of 601 caregivers, teens and children. FARP is also seeing an increased demand for its FASD worker program, to the point where there is now a waiting list for this valued resource.

FARP is increasingly recognized for its FASD expertise. This year, it delivered 17 English-language webinars to a total of 850 frontline workers and agency staff, and five webinars in French to another 210 participants. The team also launched a community of practice for Ontario's FASD workers, where 60 participants meet regularly to exchange knowledge and work toward standardizing their practice across the province.



F-Words Foundations

Principal Investigators:

Dr. Peter Rosenbaum, CanChild

Dr. Andrea Cross, CanChild

Rachel Teplicky, CanChild

1,050 people have accessed the F-Words course so far.

What it is: The F-Words are six key areas that this research team promotes as the main focus in childhood disability. Built upon the World Health Organization's International Classification of Functioning, Disability and Health framework, they encourage everyone to think about factors that are important to any child's development and well-being, such as their activities and environment. Introducing this way of thinking to families and service providers can result in measurable changes to self-reported family empowerment, parenting confidence, and experiences of family-centred service.

Next Steps: This project aims to make foundational F-Words training available across Canada by creating a free, self-paced online course in English and French. The research team will evaluate its acceptability, feasibility and usability through online surveys and interviews. They'll also compare it to an in-person version of the course.



The Integrated Navigational Support Program

Principal Investigators:

Dr. David Nicholas, University of Calgary

Dr. Lucyna Lach, McGill University

Funding Partner: The Azrieli Foundation/La Fondation Azrieli

What It Is: Families raising children with neurodevelopmental disabilities (NDDs) are often forced to navigate a confusing array of siloed, uncoordinated services spanning different sectors. They frequently struggle to determine what supports are available, which ones are appropriate for them at any given time, and how to access them—especially at key life junctures such as diagnosis, school entry or transition to adulthood.

These researchers have collaborated with local service providers in three places—Calgary, Vancouver and Yukon—to improve service navigation, bridge service gaps and reduce barriers to access. They are also sharing learnings, tips and approaches that could help other regions across the country to follow their lead.

This project is funded by a generous donation from the Azrieli Foundation/ la Fondation Azrieli to the Kids Brain Health Foundation. “Our work in neurodevelopment spans neurons to networks to neighbourhoods,” says Naomi Azrieli, Chair and CEO. “It is crucial to not only support ground-breaking research and clinical care for neurodivergent people, but also initiatives like the Integrated Navigational Support Program, to ensure individuals, families and communities can access and benefit from these resources.”

Highlights of 2021-2022: Each region is alleviating the burden that navigation places on families in ways that work for the local context. This year, the Yukon team secured ongoing funding and a permanent office for navigation services. Partners in Alberta developed training modules for professional navigators, partners in British Columbia created a navigators' community of practice and both of these teams evaluated peer-support programs where parents of children with NDDs helped other parents to identify and access resources.

At a country-wide level, the investigators hosted a conference where people shared what they've learned about building navigation capacity. They also published and distributed a community guide offering strategies for improving the odds that families of children with NDDs in any given region can get the services they need, when they need them.





OUR TRAINING INITIATIVES

Developing Leaders in the Field

KBHN's national training program prepares the next generation of professionals to foster better outcomes for children with neurodevelopmental disabilities (NDDs) and their families. It's a unique experience: Not only do participants help to lead our research projects, they also get rich learning opportunities beyond the lab, from professional-development seminars to frontline internships.

Our trainees include students, postdoctoral researchers, members of our partner organizations, people with lived experiences and other allies who are interested in NDDs.

In 2021-2022, KBHN introduced 222 trainees into its research teams. Plus, another 150 people joined them at the network's training events, courses and conferences throughout the year. They all developed competencies that will help them advance on their career paths, whether in academia, government, industry, the non-profit sector or elsewhere.

An elected organization of 14 trainees called the Policy Advisory and Research Training (PART) Committee works to enhance the networking and professional development opportunities for all KBHN trainees. In 2021-2022, PART members:

- Began developing initiatives to promote more equitable and inclusive access to network-related funding and training opportunities
- Organized a professional-development webinar series
- Played a significant role in planning the 2021 KBHN Annual Conference: they helped to select abstracts for e-posters and lightning talks, contributed to the adjudication of these presentations for awards and organized trainee events with guest speakers.



- 17 Postdoctoral fellows
- 20 Research associates
- 33 Doctoral students
- 20 Master's students
- 45 Undergraduates
- 87 Technical/Professional staff

INTERNSHIPS, AWARDS, PRACTICUMS AND FELLOWSHIPS

KBHN-Mitacs Awards

These awards fund projects that enhance services and supports for children with neurodevelopmental disabilities (NDDs) and their families across Canada. Trainees and their academic supervisors collaborate with a non-academic organization to make progress on real-world challenge areas.

Amount: \$20,000, comprising a \$5,000 contribution from KBHN that supplements the \$15,000 Mitacs Accelerate Internship award.

2021-2022 AWARDEES



Dr. Emma Duerden and Abigail Hennessey
(Western University)



Dr. Christine Gervais, Dr. Elisa Romano and
Danika DeCarlo-Slobodnik (University of Ottawa)

Early Career Investigator & Mentorship Awards

These awards strengthen the research programs of early-career faculty members or principal investigators at universities or institutes. It allows them to recruit excellent trainees, foster their connections to community partners and build their capacity as researchers in the field of neurodevelopmental disabilities.

Amount: An award amount of \$100,000 is contributed over two years. \$50,000 is co-funded by KBHN and Brain Canada while the other \$50,000 is from an eligible partner.

2021-2022 AWARDEES



Dr. Carly McMorris
(University of Calgary)

Dr. Ning Cheng
(University of Calgary)

Dr. Sarah Munce
(Toronto Rehabilitation
Institute)

KBHN-Autism Alliance of Canada Policy Development Awards

This practicum gives KBHN trainees experience in policy development, writing for an audience of policymakers and facilitating engagement with community partners.

Amount: A \$2,000 stipend and support to present at both the Canadian Autism Leadership Summit and the KBHN annual conference.

The Autism Alliance of Canada (formerly the Canadian Autism Spectrum Disorder Alliance (CASDA)) prepared a Blueprint in response to the federal government's commitment to developing a National Autism Strategy. The 2021 cohort of seven fellows led extensive consultations and co-produced three sets of policy briefs supporting this work.

2021-2022 AWARDEES



Hadas Dahary (McGill University), Dr. Jacalyn Guy (University of Cambridge), Jessi Lewis (University of Victoria), Jessica Baraskewich (University of Calgary), Dr. Wasan Nagib (McMaster University), John Sheehan (University of Victoria) and Vanessa Fong (University of British Columbia).



FAMILY ENGAGEMENT IN RESEARCH

Certified by McMaster University and co-sponsored by Kids Brain Health Network and CanChild, a 10-week course called the Family Engagement in Research (FER) Course brings families and researchers together to learn from each other about how to build a productive partnership. By doing so, it aims to shape the future of Canadian neurodevelopmental research, anchoring it in the real-life needs of children and their families.

So far, **117 researchers** and **107 family members** have completed the FER course.

Co-Developers: Dr. Andrea Cross, Connie Putterman, Donna Thomson, Dayle McCauley, Dr. Patty Solomon and Dr. Jan Willem Gorter of CanChild Centre for Childhood Disability Research at McMaster University

Highlights of 2021-2022: The course ran twice this year, allowing 61 new people to complete it. What's more, FER's founders and instructors introduced a new FER Leadership Academy to extend graduates' impact in the community. It allows them to deepen their family-engagement skills through an enhanced curriculum and small-group mentoring.

As part of the requirements for the FER course, researchers and family members partner to create resources such as the infographic and the checklist below, both developed this year. They're known as knowledge-translation tools because they help to spread knowledge and put it into action.



It was empowering because now I know what a good relationship with researchers looks like.”

PARENT AND FER GRADUATE



With increased competence and confidence, my goal now is to empower the quiet patients and families who often remain in the background to have a voice in research.”

LEADERSHIP ACADEMY GRADUATE



2021-2022'S OUTSTANDING MENTORS AND TRAINEES

Outstanding KBHN Trainee Member Awards

These awards recognize a trainee's outstanding contributions and commitment to KBHN.

2021-2022 AWARDEES



Jessi Lewis
(University of Victoria)



Dr. Samantha Micsinszki
(McMaster University)

Outstanding KBHN Promising Researcher Award

This award recognizes a trainee's research achievements.

2021-2022 AWARDEE



Behnaz Bahmei
(Simon Fraser)

Outstanding KBHN Mentor/Supervisor Awards

These awards are presented to researchers or professionals who provided outstanding, inspiring supervision or mentorship to KBHN trainees.

2021-2022 AWARDEES



Dr. Andrea Cross
(McMaster University)



Dr. Sarah J. Macoun
(University of Victoria)





THE ANNUAL CONFERENCE 2021

Centred around the theme of “Realizing Change through Partnerships and Research Innovation,” KBHN’s 2021 Annual Conference showcased fruitful partnerships in research, sparked new ones and strengthened existing ones.

With COVID-19 cases still on the rise, KBHN opted to host its annual conference online, building upon the success of 2020’s virtual event. Child psychologist and author Dr. Jody Carrington emceed the two-day gathering. “Getting connected to each other and the families that we try to treat or understand and support. That really is the answer,” she said during the opening ceremony.

KBHN-funded researchers have demonstrated this important truth in their work: They’ve partnered with families, service providers and other partners at nearly every stage of their respective projects. During conference sessions, they explained how they could not have made the same impact without these connections.

For example, the investigators who are building the Infant and Early Mental Health Hub described how they call upon Indigenous, strategic, training and research working groups to inform their resources. “I have to stress to you: these are working groups,” said Dr. Chaya Kulkarni, who leads the project. “We made it clear that we don’t need them to tell us how well we’re doing: We need them to help us understand what we need to do better, and where the gaps are that we need to fill.”

Another session showed how community agencies in Ottawa have been working with KBHN researchers to deliver a socioemotional intervention for kids with autism called Secret Agent Society—and to learn from the experience. “Research-practice partnership is so key to understanding the real-world realities of scaling, implementing and evaluating interventions in the community,” said Dr. Carrington as she introduced the speakers.

ABLE2’s Fetal Alcohol Resource Program, also supported by KBHN, described some of their many impactful partnerships, including an FASD worker program that they co-deliver with the Children’s Hospital of Eastern Ontario. The inter-organizational team behind EDIT-CP, a project that aims to ensure that cerebral palsy gets diagnosed and treated early in life, explained how the participation of caregivers is essential for effective early intervention.

Another highlight was the keynote address from Dr. Christine Imms, the Apex Australia Chair of Neurodevelopment and Disability at the University of Melbourne. She asserted that the participation of young people with disabilities and their families in research is a human right—and part of the wide range of life situations where increased participation is a desirable outcome in itself.

That said, good intentions don’t automatically lead to good outcomes. A session called

“From #HowNotToDoPatientEngagement to #BuildingBackTrust” explored the challenges of family involvement in research with constructive honesty. The panelists, who included parents, discussed what we can learn from stories of times when families were dissatisfied, or the project didn’t go according to plan.

Family engagement is one of the cutting-edge topics that have been on the minds of KBHN trainees, many of whom shared posters at virtual booths to convey their findings. Others delivered lightning talks, which distilled complex research into clear, compelling three-minute oral presentations: an impressive feat of science communication and knowledge translation. The trainee-led PART Committee and conference attendees selected two lightning talks and six posters for special recognition.

Trainees were also front-and-centre for a session called “It takes a village: Stakeholder engagement as a critical lens for the National Autism Strategy Development and Implementation.” It summarized the work achieved this year by the KBHN-Autism Alliance of Canada (formerly known as CASDA) Policy Development fellows, who led working groups consisting of people with autism, caregivers, policy-makers and service providers from across Canada. Together they created policy briefs that will help the federal government to develop a National Autism Strategy in support of social inclusion, effective services and economic inclusion.

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The Fraser Mustard lecture, delivered by Dr. Paige Church, was a moving personal account of her experiences as a neonatologist, a pediatrician and a person living with spina bifida. She spoke of how ableism influences medicine, to the point where she hid the effects of her condition from her colleagues for many years. She also offered perspectives that could prevent ableist biases from interfering with good care. “Not all conditions can be fixed,” she emphasized. “And that’s okay. Solutions to live well matter just as much.”

It was a pertinent reminder of why KBHN exists, which is to provide solutions for what matters the most to people with disabilities and their families: happy, healthy lives. As each conference session explored in its own way, partnerships are key to progressing toward this goal.



OUR NEXT STEPS

Over the past 12 years, Kids Brain Health Network has established a track record for generating relevant knowledge—and putting it to work. But even as we celebrate our successes, we’re keeping our eyes on the path ahead. Over the next five years, the network intends to pursue three complementary objectives:

Improve outcomes for children with neurodevelopmental disabilities and their families by selecting and supporting research projects that meet their needs. These will include projects that are developing new solutions, projects that bridge gaps between innovation and implementation, and projects that increase the accessibility of solutions to vulnerable and underserved people.

Accelerate the real-world impact of research innovations by building capacity within KBHN to support their scale and spread. Each project will develop an implementation or commercialization plan with the help of network-sponsored resources such as workshops, socioeconomic-impact evaluation services and an innovation advisory council.

Strengthen Canada’s research ecosystem by providing inclusive training programs for the next generation of researchers, family and community members, frontline practitioners and healthcare providers. Learning opportunities will extend beyond traditional academic training to include entrepreneurship, implementation science and family engagement in research.

We welcome supporters and partners to join us!

OUR THANKS

Kids Brain Health Network's achievements rely on the skills and contributions of hundreds of people and organizations, all of whom deserve our heartfelt thanks. We'd like to specifically thank families and caregivers for working with us. We could not do this work without them.

Network Members

Kids Brain Health Network collaborates with 22 leading academic and research institutions that become our Network Members. We thank these leading Canadian organizations who are the home of our principal investigators and researchers who have been working to develop programs, groundbreaking research, and initiatives that help improve the lives of children with neurodevelopmental disabilities and their families.

- Dalhousie University
- Holland Bloorview Kids Rehabilitation Hospital
- McMaster University
- Queen's University
- Simon Fraser University
- The Governors of the University of Alberta
- The Governors of the University of Calgary
- The Hospital for Sick Children
- The Research Institute of the McGill University Health Centre
- The Royal Institution for the Advancement of Learning / McGill University
- The University of Manitoba
- University of British Columbia
- University of Ottawa
- University of Victoria
- York University
- University Guleph
- The University of Western Ontario
- The Centre for Addiction & Mental Health
- Centre Hospitalier Universitaire Sainte-Justine
- University Health Network
- Children's Hospital of Eastern Ontario (RI)
- Carleton University–Ottawa

KBHN funded under Networks of Centres of Excellence (NCE)

We are deeply grateful to the Network of Centres of Excellence program for their funding support to KBHN as we continue the third and final cycle of funding under the federal NCE program.



Host Institution

We extend Thanks to our host institution, Simon Fraser University for their continued collaboration. SFU makes a natural home for the Network with the University's strategic focus areas including improving health across the human lifespan, emphasis on community engagement and the translation of knowledge for the greatest societal impact.



Thank you to our Partners

We'd like to underline the great contribution of our partners for bringing our innovations to life for the benefit of children with neurodevelopmental disabilities and their families.

Not-For-Profits, Foundations and Associations

Aamjiwnaang First Nation
Ability Online
AbilityWorks
ABLE2: Support for People with Disabilities
Aboriginal Head Start
Adaptive Sports Sun Peaks
Alberta Children's Hospital Foundation (ACHF)
Amiskwaciy Cultural Society
Autism Alliance of Canada (formerly CASDA)
Autism Canada
Autism Edmonton
Autism Nova Scotia
Autism Support Network
Autism Yukon
The Azrieli Foundation/La Fondation Azrieli
BC Association for Child Development and Intervention (BCACDI)
BC Centre for Ability
Bent Arrow
Bethesda Children's Services
Brain Canada
Canada FASD Research Network (CanFASD)
Canadian ADHD Resource Alliance (CADDRA)
Canadian Psychological Association
Canadian Sleep and Circadian Network (CSCN)
Canadian Sleep Society (CSS)
CanCHILD
Centre for Accessible Sport and Play
Cerebral Palsy Association In Alberta
Cerebral Palsy Saskatchewan
Children's Healthcare Canada
Children's Aid Society of Ottawa (CASO)
Children's Autism Services of Edmonton (CASE)
Connecting Windsor-Essex
Edmonton Fetal Alcohol Network
Empowered Kids Ontario
Family Support Institute of BC
Fetal Alcohol Syndrome Society Yukon (FASSY)
Georgian Bay Native Women's Association
Health Nexus
Indigenous Sport, Physical Activity & Recreation Council (ISPARC)
Jooy
Keepers of the Circle
Kids Brain Health Foundation
Kids First Inc

KidsFirst NORTH
Knowledge Institute on Child and Youth Mental Health and Addictions
Lake Ridge Community Support Services
Learning Disabilities Association of Canada
Lumenus Community Services
MITACS
Moose Cree First Nation
Mothercraft
Nishnawbe Aski Nation
Orillia Native Womens Group
Ottawa Community Foundation
ParaSport Ontario
ParticipACTION
Pikangikum Health Authority
Robson Valley Community Services
Saskatchewan Prevention Institute
Siblings Canada
Sinneave Family Foundation
Special Olympics British Columbia (SOBC)
Special Olympics Canada (SO Canada)
Special Olympics Ontario
Temiskaming Native Women's Support Group
The Sibling Collaborative
Vecova
Victoria Native Friendship Centre (VNFC)
Wisdom Keepers
York Region Early Intervention Services

Hospitals and Care Centres

Alberta Health Services
BC Children's Hospital and BC Women's Hospital
Centre for Addiction and Mental Health
The Centre for Child Development
Child Development Institute
Child Health BC
The Children's Care Clinic
Children's Hospital of Eastern Ontario (CHEO)
Children's Hospital Sydney Australia
Children's Medical Center - Tiny tots
Children's Therapy Program
Children's Treatment Network
CHU Sainte-Justine
Cree Nation Tribal Health
Daybreak Parent Child Centre
The George Hull Centre for Children and Families
Glenrose Rehabilitation Hospital

Grandview Kids
 Hamilton Health Sciences
 HNE Kids Rehab
 Holland Bloorview Kids Rehabilitation Hospital
 The Hospital for Sick Children
 IWK Health Centre
 Kids Plus
 KidsAbility Centre for Child Development
 KidsInclusive Centre for Child & Youth Development
 Kinark Child and Family Services
 Kingston Health Sciences Centre
 L.A. Scott & Associates
 Little Buddies Pediatric Therapy
 Mayo Clinic
 McGill University Health Centre
 McMaster Children's Hospital
 Montreal Children's Hospital
 Nationwide Children's Hospital
 Optimum Movement
 Owerko Centre at the Alberta Children's Hospital Research
 Institute, University of Calgary
 Queen Alexandra Centre for Children's Health
 Ron Joyce Children's Health Centre
 Rosalie Hall
 Royal Children's Hospital
 Royal Hobart Hospital
 Scarborough Centre for Healthy Communities
 SickKids Centre for Community Mental Health
 Simcoe Muskoka District Health Unit, Community and Family
 Health Department
 Sunny Hill Health Centre for Children (SHCC)
 Sunnybrook Health Sciences Centre
 SuperKids Rehab
 Thames Valley Children's Centre
 Timiskaming First Nation Health & Wellness Centre
 University Health Network
 Waypoint Mental Health Centre
 Women's and Children's Hospital (Adelaide)
 Woodview Mental Health & Autism Services
 York Hills Centre for Children, Youth and Families

Universities and Research Institutes

Alberta Children's Hospital Research Institute (ACHRI)
 Australian Catholic University
 Brock University
 Dalhousie Department of Family Medicine
 Dalhousie University
 Douglas College
 East Tennessee State University
 Humber College Institute of Technology and Advanced
 Learning
 KITE Research Institute
 McGill University
 McMaster University
 McMaster University, School of Rehabilitation Science
 Mount Saint Vincent University

Murdoch Children's Research Institute
 Northern Alberta Institute of Technology (NAIT)
 Portland State University
 Queen's University
 The Research Institute of the McGill University Health Centre
 (RI-MUHC)
 Saskatchewan Polytechnic
 Simon Fraser University
 Tel Aviv University
 University of Alberta
 University of British Columbia
 University of British Columbia-Okanagan campus
 University of Calgary
 University of Central Queensland
 University of Guelph
 University of Manitoba
 University of Melbourne
 University of Montreal
 University of Ottawa
 University of Sherbrooke
 University of Toronto
 University of Victoria
 University of Warwick
 University of Western Australia
 Western University
 York University

Government Departments and Agencies

Government of Alberta
 Public Health Agency of Canada
 Reaching Home
 BC Ministry of Children and Family Development
 Government of Prince Edward Island
 Government of Yukon
 Manitoba Liquor & Lotteries
 Ontario Health
 Ontario Ministry of Children, Community and Social Services

Industry

Babbly
 Cambridge Brain Science
 HealthTech Connex (HTC)
 Ideas for Independent Living
 Kids Uncomplicated
 Maximum Healthcare & Mobility
 The Uncomplicated Family
 Velsoft Training Materials Inc.

Schools, School Districts and Education Centres

Calgary Quest School
 Edmonton Regional Learning Consortium
 Surrey School District

OUR TEAM

We'd like to express our gratitude to our Board members for their leadership and dedication, to our Research Management Committee and Research Training Committee for their insightful guidance, to our staff and researchers for their tireless efforts.

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network | des enfants

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