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.

TABLE OF CONTENTS

4 EXECUTIVE MESSAGE
6 GROWTH BY NUMBERS
8 RESEARCH, IMPACT & INNOVATION
9 Early Identification
10 Early Intervention
13 Family Support
16 TRAINING
17 Annual Conference
18 Career Development and Training Enrichment
20 NETWORKING EVENTS & PARTNERSHIPS
23 FINANCIAL REPORTING
24 NETWORK COMMUNITY PARTNERS
28 MOVING FORWARD
EXECUTIVE MESSAGE

The 2019–2020 fiscal year marked the 10th anniversary of the Kids Brain Health Network, a significant milestone.

Over the past decade, we have worked with more than 100 Network-funded principal investigators and more than 260 affiliated researchers who have produced 83 research innovation deliverables and contributed to close to 400 NCE-supported publications. Our training program has helped to build the next generation of neurodevelopmental professionals working to improve the lives of children with neurodevelopmental disabilities and their families. In 2019-2020, 173 young professionals participated.

We are very proud of these accomplishments. Through this annual report, we would like to acknowledge the people and partnerships that have helped us along the way to develop innovative solutions which are showcased in this report.

KBHN has a strong community of deeply engaged partners and talented, hardworking individuals dedicated to neurodevelopmental research who are changing how we deliver services and supports by providing interventions that are on course for commercialization or implementation on a large scale. More importantly, our partners have served as a crucial aspect of our success. They continue to believe in the importance of the work we do and trust that we will consistently deliver on our promises.

With the close of our second research cycle, KBHN engaged in extensive consultations with researchers and partners to shift our focus to accelerating and implementing promising research to help children with neurodevelopmental disabilities and their families. As a result, by the end of our review, KBHN approved eight projects that would become our Cycle III funding focus.

We are deeply grateful to the Network of Centres of Excellence program for the third and final grant of $11.7 million that we were awarded in late 2019. This third research cycle marks the beginning of a new era for KBHN, one that will continue to focus on early identification, evidence-based interventions, and enhanced family support, with an increased concentration on putting research findings into practice.

We would also like to acknowledge with gratitude that our partners have matched every dollar provided by the NCE program. In fact, their financial contributions have surpassed the total NCE funding.

Our success is a testament to the hard work of KBHN researchers, partners, families, trainees, and staff. We are incredibly proud of the work we’ve done together, especially during a global pandemic, which presented unforeseen challenges and increased the burden on families, many of whom were already struggling to support their children with neurodevelopmental disabilities.

This annual report serves as a celebration of KBHN’s achievements in 2019-2020, as well as our previous ten years together. In addition, we want to acknowledge all those who have positively impacted the Network. Your hard work, unwavering support and dedication to this cause helped us to achieve our goals.

Now is the time to strengthen our collective resolve and to increase action across all sectors to achieve optimal care and better outcomes for all children with neurodevelopmental disabilities in Canada.

Regards,

David Kuik
KBHN Board Chair
Nicola Lewis
Chief Executive Officer
James Reynolds
Chief Scientific Officer

We are very proud of these accomplishments. Through this annual report, we would like to acknowledge the people and partnerships that have helped us along the way to develop innovative solutions which are showcased in this report.

We are very proud of these accomplishments. Through this annual report, we would like to acknowledge the people and partnerships that have helped us along the way to develop innovative solutions which are showcased in this report.

We are very proud of these accomplishments. Through this annual report, we would like to acknowledge the people and partnerships that have helped us along the way to develop innovative solutions which are showcased in this report.

We are very proud of these accomplishments. Through this annual report, we would like to acknowledge the people and partnerships that have helped us along the way to develop innovative solutions which are showcased in this report.

We are very proud of these accomplishments. Through this annual report, we would like to acknowledge the people and partnerships that have helped us along the way to develop innovative solutions which are showcased in this report.

We are very proud of these accomplishments. Through this annual report, we would like to acknowledge the people and partnerships that have helped us along the way to develop innovative solutions which are showcased in this report.

We are very proud of these accomplishments. Through this annual report, we would like to acknowledge the people and partnerships that have helped us along the way to develop innovative solutions which are showcased in this report.

We are very proud of these accomplishments. Through this annual report, we would like to acknowledge the people and partnerships that have helped us along the way to develop innovative solutions which are showcased in this report.
GROWTH BY NUMBERS

NUMBER OF PROJECTS (TOTALS for EACH CYCLE)

NCE & PARTNER CONTRIBUTIONS
($M TOTAL AMOUNT per FISCAL YEAR)
(includes cash and in-kind)

Cycle I Cycle II

KYB Foundation

Provincial/ Federal

NCE
KBHN focuses on three significant challenges across virtually all neurodevelopmental disabilities: **early identification, early intervention, and increased family support.**

Our researchers are on the verge of delivering game-changing interventions with significant implementation potential on a large scale. In year 10, KBHN achieved several successes that demonstrate our collective impact within the neurodevelopmental research community. Research programs include three focus areas: early identification, early intervention, and family support.

### Genomic Assessment Tool

Fetal Alcohol Spectrum Disorder (FASD), which results from prenatal alcohol exposure, is the most common cause of neurodevelopmental impairments in the western world, with an estimated 3-5% prevalence in Canada and as high as 11% in some communities. Diagnosing the disorder is time-consuming and costly. However, early diagnosis of children at risk of developing FASD would allow for earlier interventions that could significantly reduce secondary FASD disabilities and improve their quality of life. The Epigenetic Screening for FASD research team is developing a genetic assessment tool called the “FASD Code.” It will enable early identification of children at-risk for the effects of prenatal alcohol exposure (PAE) and early access to the care and education programs.

Designed for replication and scalability at the community, provincial, or national level, FASD Code will pave the way for robust, personalized, and cost-effective identification of prenatal alcohol exposure and FASD for any individual, prioritizing at-risk infants and children who do not have an identified history of PAE or who are not yet symptomatic. The project also involves determining how to implement the genomic assessment tool to adapt to local communities.

### Infant EEG NIRS

Early diagnosis and early intervention for children with neurodevelopmental disorders (NDD) can help improve future development, increase social integration and pave the way for better academic success. Scientists and clinicians have been increasingly interested in early diagnostic tools to assess brain function and cerebral activity, known as electroencephalographic (EEG) and optical imaging (near-infrared spectroscopy, NIRS). These tools are low-cost, non-invasive, and can assess brain function in very young children. They allow for the possibility to detect neurodevelopmental disorders earlier than by using behavioural markers.

The Infant EEG/NIRS Group aims to bring electroencephalography (EEG) and near-infrared spectroscopy (NIRS) into clinical practice for early screening for neurodevelopmental disorders. The project addresses a significant barrier to implementing EEG/NIRS in a clinical setting: the lack of meaningful and predictive baseline data from the general population. This research may eventually help identify new treatment methods, allow psychotropic treatment surveillance in infants and reduce long-term care costs. In addition, these results will benefit all patients showing risk factors for abnormal neurological development across Canada.
Nurturing the Seed

As a result of intergenerational trauma, Indigenous children in Canada have an increased risk of developmental delays and poor mental health compared to non-Indigenous Canadians. This inequity is complicated by social factors such as marginalization and a lack of culturally informed interventions. KBHN researchers drew inspiration from a screening and intervention program called Hand in Hand, which can improve the developmental trajectories of preschoolers who are showing signs of delays and mental health issues. Together with Elders and advisors from several Indigenous communities, researchers created a new Nurturing the Seed program, which incorporates worldviews, values, rituals, and parenting practices distinct to Indigenous communities in Canada. It also contains additional guidelines to help any frontline workers who are not Indigenous build the cultural sensitivity and aptitude they’ll need to deliver the program.

Dino Island

Dino Island (formerly Caribbean Quest) is a tablet-based game-like intervention designed to improve attention, short-term memory, and self-regulation for children with neurodevelopmental disabilities. In 2020, Dino Island was launched on the Paraean Gaming Platform’s Kids Digital Health Network. This website provides children with a safe and readily available space to enjoy and benefit from therapeutic intervention. There is also a companion website that introduces evidence-based strategies for teaching problem-solving techniques to children. Its accessibility also breaks down barriers: remote or resource-limited communities can use it to tackle developmental needs that would otherwise go unaddressed. Results show that Dino Island can significantly improve the quality of life and outcomes for the thousands of children living with neurodevelopmental disabilities worldwide who experience attention and executive functioning problems. Researchers estimate that Dino Island will directly impact 4,500 – 5,000 children and families over the next three years.

Social ABCs

Most Canadian provinces and territories offer government-funded interventions to people with a confirmed diagnosis of Autism Spectrum Disorder. However, because of long wait lists—first for diagnosis and then for treatment—many children don’t get the help they need. To address this problem, a program called Social ABCs offers accessible early intervention to the families of preschoolers who show signs of ASD or social-communication delays. With guidance from trained coaches, parents learn to promote shared attention and speech—the building blocks of communication—through everyday activities and interactions.
Sound Sensitivity Solutions for ASD

Children with neurodevelopmental disorders (NDDs) often experience hypersensitivity to sound. This sensitivity can be so severe that it prevents people with NDDs from fully participating in social settings. Researchers have developed a personalized device, a set of headphones connected to a smartwatch that can selectively filter out undesired sounds while not distorting essential sounds, like speech. The device will be designed for school-aged children with ASD but will be scalable to children and adults with other NDDs. KBHN researchers have partnered with MetaOptima, a tech-health company, to help build the prototype and commercialize the technology. They have also partnered with Surrey School District in B.C. to consult on the design and to help evaluate the device in a school setting.

Fetal Alcohol Resource Program (FARP)

Families and individuals with Fetal Alcohol Spectrum Disorder (FASD) often struggle to access supports, sometimes because they don’t know services exist and sometimes don’t meet the inclusion criteria. The Fetal Alcohol Resource Program (FARP), developed in partnership with ABLE2 (formerly Citizen Advocacy Ottawa), plays a navigator role, helping families connect to organizations and agencies that provide housing, child welfare, justice, health care, and education services. The program also offers customized workshops to inform people about issues and barriers that children with FASD face, and approaches that may assist them in supporting these kids. FARP has provided these sessions to more than 4,000 individuals in schools, hospitals, and youth justice programs. The team received 600+ requests in diagnosis, counselling, and educational supports and have also provided intensive support to families in crisis, some of whom were at risk of an adoption breakdown. In 2018, FARP was contracted by Children’s Hospital of Eastern Ontario to deliver the Ontario FASD Worker program to three regions of Eastern Ontario, and FARP has also expanded its services to the adjacent areas in Ontario.

Chatbot Personalized Interventions

KBHN researchers are developing an artificial intelligence software application – a “chatbot” – to act as a personal assistant/coach to support individuals with a neurodevelopmental disability by offering targeted interventions and personalized care. In addition, the chatbot is being designed to converse with parents and point them toward the most valuable resources for their child. Developed in collaboration with health, education, and social science specialists, the chatbot will be tested with the project team’s parent advisory group.

Better Nights Better Days for Children with Neurodevelopmental Disabilities

Up to 90% of children with neurodevelopmental disorders (NDDs) experience sleep problems, particularly insomnia, which refers to difficulties falling asleep, staying asleep, and waking up in the morning. Treating sleep problems in children with NDDs is critical. Yet, these children rarely receive the interventions they need due to limited access to programs, insufficient training of healthcare providers in sleep problems in children with NDDs, and logistical barriers for families to engage in traditional face-to-face interventions.

To address this, KBHN researchers developed an online intervention for parents and primary caregivers to help children sleep better. In addition, the research team created a direct-to-consumer sustainability model for the Better Nights Better Days for Children with Neurodevelopmental Disabilities program. Through partnerships with Velsoft Training Materials Inc. and the Office of Commercialization and Industry Engagement at Dalhousie University, a commercial license agreement has been drafted and is ratified for wide-scale implementation. The Better Nights Better Days adaptations for children with NDD is now undergoing recruitment as a randomized clinical trial to validate the usability and effectiveness in this community.

Family Support

Families and individuals with Fetal Alcohol Spectrum Disorder (FASD) often struggle to access supports, sometimes because they don’t know services exist and sometimes don’t meet the inclusion criteria. The Fetal Alcohol Resource Program (FARP), developed in partnership with ABLE2 (formerly Citizen Advocacy Ottawa), plays a navigator role, helping families connect to organizations and agencies that provide housing, child welfare, justice, health care, and education services. The program also offers customized workshops to inform people about issues and barriers that children with FASD face, and approaches that may assist them in supporting these kids. FARP has provided these sessions to more than 4,000 individuals in schools, hospitals, and youth justice programs. The team received 600+ requests in diagnosis, counselling, and educational supports and have also provided intensive support to families in crisis, some of whom were at risk of an adoption breakdown. In 2018, FARP was contracted by Children’s Hospital of Eastern Ontario to deliver the Ontario FASD Worker program to three regions of Eastern Ontario, and FARP has also expanded its services to the adjacent areas in Ontario.
Physical Activity Program

Physical activity programs (now Kids Action Coaching) are an effective, low-cost intervention to help children living with neurodevelopmental disabilities and their families. In addition to promoting physical literacy, community-based physical activity programs give these children the opportunity to participate in activities with peers, create the context for cognitive functions development and learning, and offer psychosocial benefits for parents and caregivers. As a result, children who engage in physical activity programs report enhanced physical abilities, cognitive functions, executive functioning, social inclusion, and activities of daily living. The team is now working with Indigenous and rural communities to develop adapted programs. Also underway are new coaching interventions that will be specially adapted for children under the age of four. In addition, there will be an innovative coaching intervention to support the integration of children with neurodisabilities into physical activity programs at school.

System Navigation for NDD

Children with neurodevelopmental disabilities (NDDs) often navigate a confusing patchwork of uncoordinated services in different sectors, organizations, and layers of government. Research shows that families frequently struggle to determine what supports are available, appropriate, and accessible—especially at crucial life junctures such as diagnosis, school entry or transition to adulthood. Research supported by Kids Brain Health Network is focused on understanding navigational barriers to improve systems and enhance navigational experiences for children and their families.

This extensive, interdisciplinary program is working in three distinct regions (British Columbia, Alberta, and the Yukon) to achieve the overarching goals of:

- improving navigational systems by making them coordinated and person/family centred,
- building capacity across a continuum of care and across sectors (education, health, social services) in collaboration with NGOs and government.

This project addresses the unique needs of each region by building on local strengths to solve local problems. In Vancouver, for example, our partners realized that after a child received an autism diagnosis at the Sunny Hill Health Centre for Children, their families were left wondering what to do next. Now, each family is automatically referred to Autism Information Services BC. This agency guides them in taking their next steps. Meanwhile, the Yukon team hired a navigator in a remote community, bridging gaps and connecting families with services and learning new ways of navigating systems in rural or remote communities. In Edmonton, the team is co-developing, piloting, and evaluating a peer/professional-based navigation program for parents and contributing to a regional navigational resource.

Family Support

Family Support

Family Support continued

Family Support continued

Physical Activity Program

Physical activity programs (now Kids Action Coaching) are an effective, low-cost intervention to help children living with neurodevelopmental disabilities and their families. In addition to promoting physical literacy, community-based physical activity programs give these children the opportunity to participate in activities with peers, create the context for cognitive functions development and learning, and offer psychosocial benefits for parents and caregivers. As a result, children who engage in physical activity programs report enhanced physical abilities, cognitive functions, executive functioning, social inclusion, and activities of daily living. The team is now working with Indigenous and rural communities to develop adapted programs. Also underway are new coaching interventions that will be specially adapted for children under the age of four. In addition, there will be an innovative coaching intervention to support the integration of children with neurodisabilities into physical activity programs at school.
The KBHN Training Program helps young professionals acquire cross-disciplinary skills and experience, build their networks, and advance their careers in academic and non-academic career paths. Through partnerships with organizations across Canada, we offer an extensive range of internships, pre-professional placements, exchanges, awards, and longer-term training opportunities that help build capacity in community engagement and policy development. Our unique training and mentorship environment allows researchers, professionals, and trainees to collaborate with families, family advocates, and community partners to create and implement research programs. In addition, KBHN trainees have the opportunity to participate in a range of activities and presentations at our annual conference.

With the support of Network research projects and Brain Canada-KBHN Training Awards, 173 young professionals participated in our Training Program in 2019-2020, including:

- 12 Research Associates
- 28 Postdoctoral Fellows
- 38 Doctoral Students
- 30 Master’s Students
- 23 Undergraduates
- 42 technical staff

In addition, 231 people have joined the Network as Associate Trainee members. Although they are not affiliated with individual KBHN supported research projects, many Associate Trainee members have participated in KBHN events and conferences throughout the year. Last year, there were 50 new trainee members in this group.

Trainees were instrumental in coordinating the conference policy forum: “Breaking Down Barriers: Informing Policy through Research.” In this panel, decision-makers and community stakeholders discussed their perspectives on the role of researchers in informing policy development, including practical approaches for communicating evidence to decision-makers. Ultimately, the session explored methods for communicating findings, showcased KBHN work as examples, and reflected on the role of researchers and stakeholders in the policy development process. Five trainees collaborated with Network investigators to develop research policy briefs, presented this work, and shared their novel experience in this area.

Trainee Lightning Talks

Lightning Talks are short presentations that highlight key research findings and outcomes that will impact an area of study. During these sessions, Trainees and young professionals had the opportunity to take the stage to showcase their cutting-edge research, stimulate discussion, and attract traffic to their posters. The 2019 Kids Brain Health Conference featured ten Trainees: Analyssa Cardenas, Sarah Raza, Emily Colks, Christina Rohn, Heather Shearer, Brittany Pinkay, Ayesha Siddiqua, Sarah Hutchison, Gabrielle López–Arango and Kinga Pozniak.

Poster Reception

Poster presenters shared research study results, community engagement activities, and knowledge mobilization initiatives to demonstrate what is happening across the KBHN community space and have the chance to Network with old and new friends. Nearly 50 posters from Trainees and researchers were presented at this year’s annual conference. Network Trainees indicated a desire to use this forum not just as an opportunity to share their work but also as a more formal way to improve their presentation skills for future events.
Career Development and Training Enrichment

Opportunities for Trainees extend well beyond the annual conference. The following are other ways that Trainees can engage with KBHN projects.

Family Engagement in Research (FER) Certificate Program

A project tends to have greater relevance when it arises directly from the needs and priorities of families rather than solely the interests of researchers or their funders. Despite this, scientists and families have relatively few chances to connect. Over the past 2 years, KBHN has worked with the KBHN Family Engagement Team in collaboration with CanChild and McMaster University Continuing Education Program to build capacity in family engagement in research, planning, and implementation. As a result, graduates of the course are more capable and confident to partner at various stages of the research process and can contribute to and engage in neurodevelopmental research.

Community Internships

Two KBHN Community Internships were awarded to the “Nurturing the Seed” research project team. The interns engaged with several Indigenous communities across Canada and were supervised by a community agency partner (Infant Mental Health Promotion). The opportunity to be embedded in the community allowed these interns the chance to interact closely and learn from community leaders and Elders. It also provided interns with first-hand knowledge on how community-based research is conducted and demonstrated the importance of establishing a prior relationship to gain trust and show respect for Indigenous ways of knowing and being.

Policy Practicum Fellowships

The KBHN Training program initiated the development of "Policy Practicum Fellowships" to give Trainees experience in working with policy and decision-makers at the government, organizational and community levels. For example, KBHN partnered with the Canadian Autism Spectrum Disorder Alliance (CASDA) to assist with the realization of CASDA’s Blueprint in response to the federal government's commitment to developing a National Autism Strategy. In early 2020, the CASDA-KBHN “Policy Practicum Fellowships” were launched, and 5 fellowships were awarded to KBHN graduate students and postdoctoral fellows ($5000 award over a 6-month term).
NETWORKING EVENTS & PARTNERSHIPS

KBHN is proud to work with a community of dedicated organizations and individuals across many different sectors. These partners range from non-profits, academic institutions and businesses dedicated to finding solutions in early identification, evidence-based interventions and family support to promote, scale, and spread innovations that can enhance the lives of children and youth living with an NDD. Partnerships have served as a crucial aspect of KBHN’s success and play a critical role in delivering treatment and supports. Following are some highlights:

Indo-Canada Workshop
KBHN co-sponsored the international Indo-Canadian Autism Network Symposium (I-CAN 2020) held February 17-19, 2020, in Hyderabad, India. The Symposium aimed to build capacity by forming a global network to connect clinicians and researchers from Canada and India to share and exchange knowledge and experience.

With a focus on diagnosis, early intervention, complex presentations, and family support, I-CAN 2020 included a series of 2-day training workshops that followed a 1-day roundtable meeting devoted to engagement and network development.

The Symposium featured a plenary session on “Early Detection and Diagnosis of Autism Spectrum Disorder” presented by Dr. Lonnie Zwaigenbaum (KBHN ASD Research Program lead). In addition, training workshops were held on ASD diagnosis, led by Dr. Zwaigenbaum, and the Social ABCs intervention, led by KBHN clinical research associates Kate Bernardi and Erin Dowds. These workshops emphasized practical applications for implementation into the clinical and research activities of local Indian health agencies.

The Divis Foundation for Gifted Children also sponsored the event with support from the University of British Columbia.

CHC-KBHN Conference
KBHN held our 2019 annual conference in conjunction with our long-time partner Children’s Healthcare Canada (CHC), to strengthen connections. Our community and network partners have always shared a similar vision. We all strive to find better ways to help families cope with the challenges of navigating systems and accessing support for their children’s complex medical and psychosocial needs.

Conference speakers shared their knowledge and enthusiasm on research discoveries and therapeutic innovations to inform policy and change work. With a theme of “Building Partnerships that Impact Communities,” KBHN and CHC aimed to engage, inspire, and encourage the exchange of ideas among researchers, communities, and patients and families. In doing so, we will continue to seek solutions to address the challenges faced by children and families impacted by neurodevelopmental disabilities.

The closing CHC plenary featured disability advocate Maayan Ziv, who from a young age has been a trailblazer for accessibility and inclusion. In her speech, Ziv challenged the world to reframe the definition of accessibility.
KBHN/CCLF Early Years Literacy Consultation

KBHN, in partnership with the Canadian Children’s Literacy Foundation (CCLF), cohosted the KBHN/CCLF Early Years Literacy Consultation in Toronto on Thursday, November 14, 2019. At the time, CCLF was a new Canadian charity with the bold mission of enabling Canada’s children to achieve their full potential.

The event provided researchers, early literacy experts, evaluation specialists, and those with in-the-field experience a chance to connect. The workshop’s purpose was to guide CCLF in designing a program to address significant at-risk populations with an initial focus on early literacy and the pre-school years.

Through this consultation process, CCLF hoped to gather a range of opinions about the best contact points for an early/emergent literacy intervention and explore the best evaluation methods to measure program effectiveness. This workshop was part of the Network’s overall goal of exploring opportunities to improve children’s developmental outcomes.

KBHN-AIDE Virtual Research Panel


FINANCIAL REPORTING

As at March 31, 2020

Receipts

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions from NCE</td>
<td>2,962,202</td>
</tr>
<tr>
<td>Contributions from KBHF</td>
<td>384,180</td>
</tr>
<tr>
<td>Contributions from IHSTS</td>
<td>245,265</td>
</tr>
<tr>
<td>Contributions from ESDC</td>
<td>69,000</td>
</tr>
<tr>
<td>Conference registration fees and other support</td>
<td>66,351</td>
</tr>
<tr>
<td>Amortization of deferred capital contributions</td>
<td>1,892</td>
</tr>
<tr>
<td><strong>Total Receipts</strong></td>
<td><strong>3,728,890</strong></td>
</tr>
</tbody>
</table>

Expenditures

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research and knowledge mobilization grants and training</td>
<td>2,447,368</td>
</tr>
<tr>
<td>Operating and Administration</td>
<td>686,251</td>
</tr>
<tr>
<td>Travel, meetings and networking</td>
<td>333,008</td>
</tr>
<tr>
<td>Professional and consulting fees</td>
<td>212,335</td>
</tr>
<tr>
<td>Communications</td>
<td>65,914</td>
</tr>
<tr>
<td>Insurance</td>
<td>9,952</td>
</tr>
<tr>
<td><strong>Total Expenditures</strong></td>
<td><strong>3,754,728</strong></td>
</tr>
</tbody>
</table>

(NCE) Networks of Centres of Excellence (KBHF) Kids Brain Health Foundation (IHSTS) Institute for Health System Transformation and Sustainability (ESDC) Employment and Social Development Canada
NETWORK COMMUNITY PARTNERS

Project Partners

1. AACPDM (American Academy for C.P. and Developmental Medicine
2. Aamjiwnaang First Nation
3. Adventure Place
4. AIDE: Autism and Intellectual Disability Exchange Network
5. Alberta Health Services
6. Atlantic Aboriginal Headstart
7. Autism Edmonton
8. Autism Yukon
9. Azrieli Foundation
10. Canadian Association of Paediatric Health Centres (CAPHC)
11. Centre for Child Development
12. Cerebral Palsy Association in Alberta
13. Cerebral Palsy Foundation
14. Challenge Disability Resource Group
15. CHEO
16. Children’s Aid Society of Ottawa
17. Children’s Autism Services of Edmonton
18. Children’s Healthcare Canada
19. CIBC
21. Cree Nation Tribal Health Centre
22. Dalhousie University
23. Department of Justice - Corrections Branch
24. District of Temiskaming Elders Council
25. Edmonton and Area Fetal Alcohol Network
26. Edmonton Public Schools
27. Edmonton Regional Learning Consortium
28. Elk Island Catholic Schools
29. Family Support Institute of B.C.
30. Fetal Alcohol Syndrome Society Yukon

Network Members

1. Dalhousie University
2. Holland Bloorview Kids Rehabilitation Hospital
3. McMaster University
4. Queen’s University
5. Simon Fraser University
6. The Governors of the University of Alberta
7. The Governors of the University of Calgary
8. The Hospital for Sick Children
9. The Research Institute of the McGill University Health Centre
10. The Royal Institution for the Advancement of Learning / McGill University
11. The University of Alberta
12. The University of British Columbia
13. The University of Calgary
14. The University of Manitoba
15. The University of Ottawa
16. The University of Victoria
17. The University of Western Ontario
Project Partners continued

31. Geneva Centre for Autism
32. Georgian Bay Native Women’s Association
33. Glenrose Rehabilitation Hospital, Edmonton
34. Greater St. Albert Catholic Schools
35. Health Nexus
36. HealthTechConx
37. Help and Hope for Families Society
38. Holland Bloorview Kids Rehabilitation Hospital
39. Indigenous Sport, Physical Activity & Recreation Council (ISPARC)
40. Infant Mental Health Program
41. Inuuqtigiit Centre for Inuit Children, Youth and Families
42. iSpark Consulting Inc.
43. “Kids Come First” Ontario Health Team
44. Keepers of the Circle
45. Kerry’s Place Autism Service
46. Kids First La Ronge
47. Kinark Child and Family Services, York and Durham regions
48. Lake Ridge Community Support Services
49. Manitoba FASS Clinic
50. Manitoba Liquor and Lotteries
51. McMaster Children’s Hospital
52. Michael Smith Foundation for Health Research
53. Mi’kmaw Family Support Miramichi
54. Ministry of Children and Youth Services
55. Mohawk Nation of Akwesasne
56. Mosakahiken (Moose Lake) First Nation
57. Native Child and Family Services
58. Northern Alberta Institute of Technology
59. Ontario Brain Institute
60. Ontario Centre of Excellence for Child and Youth Mental Health

61. Orilla Native Women’s Group
62. Panacea Gaming Platform
63. ParticipACTION
64. Public Health Agency of Canada
65. Queen’s University
66. Special Olympics BC
67. Special Olympics Canada
68. Surrey Hill Health Centre for Children
69. Surrey Place Centre, Toronto
70. Surrey School District, Surrey, BC
71. Tsimshian Native Women’s Support Group
72. The Alva Foundation
73. The Asante Centre, Maple Ridge, BC
74. The Hebrew University of Jerusalem
75. The MILE Program
76. The Uncomplicated Family / Kids Uncomplicated
77. University of Toronto – Faculty of Kinesiology and Physical Education
78. Valors
79. Velsoft
80. Wabano Centre for Aboriginal Health
81. Wisdom Keepers
82. Woodview Autism and Mental Health Services
83. Yukon Government (Department of Health and Social Services)
84. Yukon Interagency Network on Disability (YIAND)
85. Yukon Legal Services Society
Due to high demand, the Social ABCs Program is expanding. The team is developing a training hub, building capacity and enabling service providers and agencies across the country to administer the intervention. The hub will allow for in-person training, and also online, improving access to the training for people in remote regions.

Nurturing the Seed is focused on Indigenous children, but the program is a relevant and effective intervention for all children at risk of poor development. The Infant and Early Mental Health Hub for Training, Resources, & Tools will provide access to the components used to implement Nurturing the Seed, and broaden the availability of these important interventions. These include training, coaching, access to multiple tools and resources and regular access to new and cutting-edge practices.

The Dino Island team has developed a plan for commercializing this game-based intervention. The researchers anticipate a substantial market for Dino Island, given the scarcity of effective, evidence-based programs targeting attention and executive function, and the prevalence of these challenges among children with neurodevelopmental disabilities.

The Better Nights, Better Days program for children with NDDs is working to ensure that families have direct access to this effective intervention. In addition, the team is creating a new implementation plan to sustain this program through the commercialization of the product, and evaluating the user’s experience (e.g., delivery and use, fidelity, overall satisfaction).

The System Navigation team will continue to increase capacity, building on the extensive local networks of partners in each region, and sharing best practices. Ultimately, the goal is to improve service access and navigation, especially concerning integration across the systems of care for families raising children with NDDs.

The Physical Activity Program team aims to have a transformative effect on community-based physical activity interventions. An additional $437K in funding from the B.C. Ministry of Health will support a three-year extension of the project to connect with Indigenous families and rural communities within the province (2019-2022). The project team also plans to implement the new coaching model outside British Columbia, initially focusing their efforts in Prince Edward Island, Alberta and Ontario.

The Fetal Alcohol Resource Program (FARP) has a leadership role with Ontario’s 34 FASD (Fetal Alcohol Spectrum Disorder) workers, hosting knowledge exchange events and creating a community of practice to standardize service delivery across the province. In addition, the team is developing an FASD walk-in clinic, expanding the impact of the annual FASD Awareness Walk, and continuing with the Eastern Ontario FASD Symposium. To extend the research of the program beyond its existing regions, the FARP team will provide workshops on a fee-for-service basis.

The FASD Epigenetics team is exploring how to use the FASD Code to implement early screening of children who are at risk of the disorder, and determining how to implement the genomic assessment tool to adapt to local communities through culturally sensitive approaches.
Partner-focused and solutions-driven

CELEBRATING 10 YEARS OF IMPACT