





A CANADIAN NETWORK OF CENTRES OF EXCELLENCE annual report 2016-2017



vision

The work of Kids Brain Health Network will meaningfully improve quality of life for children with neurodisabilities and their families through early diagnosis, effective treatment, and support for caregivers.

mission

Kids Brain Health is the first national research network in Canada focusing on brain development and neurodisabilities. Our national multi- and trans-disciplinary network is dedicated to ensuring the best possible outcomes for affected kids and their families. Kids Brain Health Network focuses its funding on integrated, team-based research that engages families, clinicians, and other stakeholders and partners within Canada and internationally. Leveraging and enhancing the talents of new and seasoned researchers and in collaboration with our partners, we translate our discoveries into effective tools for diagnosis, treatment and family support, as well as for changes in policy and practice.

objectives

IMPACTFUL DISCOVERY produced by exemplary collaborative research in high-impact areas identified by our partners, patients, and families.

TRAINING that develops the next generation of developmental neuroscientists with enriched learning opportunities as well as skills to excel in the workforce.

AWARENESS that engages partners in accelerating social and economic policy change to improve quality of life for children with neurodisabilities and their families, and society as a whole.

PARTNERSHIP that expands the reach of the Kids Brain Health Network and its impacts, maximizing the potential of Network discoveries and their uptake and implementation through integrated knowledge translation and valorization.

key to themes

To help readers locate content of interest within the themes of this report, relevant sections regarding specific neurodisabilities are highlighted with distinctive coloured icons:



table of contents

page

- 5 Message
- 6 Kids Brain Health by the Numbers
- 8 theme 1. Access to Early Diagnosis and Services
- 11 theme 2. Supporting Social Skills and Self-Regulation
- 16 theme 3. Schools and Children with Neurodisabilities
- 20 theme 4. Transitions
- 27 theme 5. Equity and Access across Disorders and Geography
- 33 Research and Training Program Update
- **36 Financial Statements**
- 48 Research Projects & Programs
- 52 Network Community

support

The work of Kids Brain Health Network is made possible by the Networks of Centres of Excellence, a program of the federal government aimed at focusing a critical mass of Canada's research resources on our social and economic challenges, including commercializing and applying home-grown research breakthroughs, increasing private sector R&D, and training highly qualified personnel. Kids Brain Health gratefully acknowledges host support from the University of British Columbia and the Child and Family Research Institute.





a place of mind THE UNIVERSITY OF BRITISH COLUMBIA



responding to the needs of our partners and stakeholders

integration,

the seventh annual report of Kids Brain Health Network's activities and impacts, reflects our growing commitment to partner-driven research, training and knowledge translation, where our endeavours integrate with our partners' priorities and success.

Kids Brain Health Network wishes to thank the individuals who give of their time and share their knowledge in the interest of increasing the Network's capacity to deliver evidence that helps our partners deliver improved diagnosis, treatment and support to families raising children with neurodisabilities. message

FROM KBHN'S BOARD CHAIR, SCIENTIFIC DIRECTOR AND EXECUTIVE DIRECTOR

This first year under our new banner as Kids Brain Health Network has been one of sweeping change.

Our rebranding has not just been semantic—our new name represents our increasing orientation to families, community partners, and other stakeholders—the beneficiaries and end users of our discoveries and insights.

Engagement is now a cornerstone of Network activity, and a strong influence on our line of sight through the three remaining years of our current mandate, and beyond. We are hitting our stride in building our research results for social and economic impact: impact that will change the lives of Canadian families raising children with neurodisabilities.

In these pages, you will read about what's involved in getting to impact and how we're achieving it. Our primary emphasis on family engagement and collaboration with partners is showcased in five powerful themes that demonstrate the resonance between our way forward, and what stakeholders, in their own words, have told us they need: access to diagnosis and services; more equity across disorders and geography; support for children and youth in transitions; help building better self-regulation and social skills in children and youth; and changes in education that need to happen so that children with neurodisabilities can succeed. These needs emerge from our commitment to listening, and translating what we hear into action. At our 2016 Brain Development Conference, and through targeted and rigorous interviews and a national online survey, we have heard these themes articulated with clarity and passion.

The Board of Directors, Scientific Director, the Management Team, and the membership comprised of stellar investigators are working together to transform the Network both in name and substance.

In addition to the stories in this report, we would like to highlight additional successes we have had in the past year. These include:

• Collaboration in BC with three different provincial ministries who have come together to advance projects focused on identification and treatment of children with NDDs

• An opportunity to train our next generation of developmental neuroscientists through a collaboration between KBHN, Brain Canada, and leading Canadian universities and institutes

• A philanthropic commitment to support establishment of a public-facing resource and system navigation program in neurodisabilities in BC, Alberta and the Yukon

 Our \$25M sister network, CHILD-BRIGHT, is opening its first clinical trials. We share a number of key investigators and have a strong overlap in our objectives

We have many other examples and stories emerging from our Network that share these attributes: providing our partners with affordable and innovative tools for screening and diagnosis; with a range of treatments that address core concerns; with proven methods of supporting families toward better outcomes; and with unprecedented, evidence-based insights that can shape better policies and practices.

Dr. Sheila Laredo Board Chair



Dr. Daniel Goldowitz Scientific Director



Thomas Philpott Executive Director







Decrease in Year-4 HQP reflects completion of Opportunities Initiative projects

theme 1

Access to Early Diagnosis and Services

"Early identification and early intervention for children with neurodisabilities are critical, yet lacking in many parts of the country."

From: Stakeholder Engagement Activity Report 2017 | Kids Brain Health Network KT Core

Two Kids Brain Health Network projects are working with community partners and exploring new collaborations to promote access to screening and early diagnosis that Canadian families say they want and need.



FASD

The most vulnerable among us: picking up developmental flags and targeting intervention for children in care

More than 60,000 children are in care in Canada: the Hand in Hand program gives a voice to the very youngest

When children go into care in Ontario, ensuring they have a voice in determining where and how they want to live is enshrined in law via the 2016 Katelynn's Principle Act.

School-aged children can and do speak for themselves in the placement process, but babies and toddlers coming to the attention of the Children's Aid Society of Toronto [CAST]* might have remained voiceless, but for a project led by Hospital for Sick Children researcher Chaya Kulkarni. In a protocol that combines established and novel tools, workers at CAST are able to identify and support children as young as a month of age who are showing signs of developmental delays. "What the screening and intervention project enables us to do is get really detailed data about how the child is managingwhere they are at risk for delays. This enables us to develop a plan of care that can be used by the foster parents and the biological parents in improving the child's developmental trajectory," says Brenda Packard, a child welfare supervisor with CAST.

Using two Ages and Stages Questionnaires (ASQ3 and ASQ Social Emotional 2), Packard and other CAST workers look at a range of capacities, including communication, problem solving, personal and social skills, and fine and gross motor functioning, as well as social and emotional development. "This brings out the voice of a very young child," explains Packard, a new KBHN trainee who has led the project within CAST since its inception.

If lags are detected, workers collaborate with families and caregivers to develop an evidence based developmental plan based on Dr. Kulkarni's Hand in Hand manual. Activities are tailored to reflect the resources available to the family and their overall situation.

Because the tools are not diagnostic, any practitioner can be trained to use them. A trio of benefits result, according to Dr. Kulkarni. First, screening is no longer dependent on access to a primary care doctor; second, the tools are cost-effective; and third, they are easily accessible even in remote regions. Several communities in northern Saskatchewan are working toward implementing both the questionnaire and Hand in Hand development plan.

MAKING THE MOST OF TIME BEFORE FORMAL DIAGNOSIS

"Ideally, anyone working with children under five on a regular basis should be able to screen and create a plan," says Dr. Kulkarni. At CAST, all field and in-house personnel are trained in using the ASQ, which puts everyone involved in a child's care on the same page with a concrete indication of how the child is functioning.

"This provides a way for practitioners and caregivers to make the most of long wait times for more intensive assessments and services," adds Dr. Kulkarni. The approach also provides a significant leg up over the barrier posed by requiring diagnosis before intervention can begin. The typical wait is six to nine months for formal assessment, and an additional nine to 11 months for access treatment in Ontario.

"Everybody thinks you need a diagnosis to do anything," says Dr. Kulkarni. "What you need to know is developmental status now, and figure out what is a manageable and tangible next developmental milestone for this child that could become a goal."

The protocol is being studied in trials of both general populations and children in the foster care system. With 800 screenings completed, CAST has started collecting data, and new project sites and partnerships have been established in Calgary. Brenda Packard and former KBHN trainee Carmela Paolozza have both trained foster parents on the use of the questionnaire and intervention planning.

FIRST NATIONS COMMUNITIES HELP CUSTOMIZE HAND IN HAND

Kulkarni's Infant Mental Health team has also had a role in adapting Hand in Hand into Nurturing the Seed, an intervention plan designed specifically for non-Aboriginal workers supporting Aboriginal families.

"Nurturing the Seed provides a better understanding of cultural issues, the barriers and the challenges, the historical trauma, and how that can impact their willingness to engage with services," says Dr. Kulkarni. "It also provides strategies that are much more culturally appropriate."

*Learn more about our partner Children's Aid Society of Toronto http://www.torontocas.ca/

Parent screen for infants reliably identifies at-risk siblings of children with autism

Questionnaire helps turn niggling doubts into effective communication tool for parents and health care providers

Parents are key participants in an early screening project that identifies siblings of children already diagnosed with autism when as young as six months of age. The core of the project is the Autism Parent Screen for Infant (APSI), a parent questionnaire developed by two KBHN researchers, Dr. Susan Bryson and Dr. Lonnie Zwaigenbaum and their teams.

The APSI consists of 26 questions asking parents to provide information about symptoms and behaviors that are both directly and indirectly related to autism. The novelty of the tool is that it can be used to detect signs of autism in children 18 months before diagnosis is typically made in Canada.

This year, KBHN post-doctoral trainee Dr. Lori Sacrey led a validation study of the APSI that confirmed the tool was effective at detecting early signs of autism in children at the target age of six months, and demonstrated that the tool is even more accurate when used with toddlers, up to the age of two.

The APSI can identify signs of autism in six-month-old babies

Dr. Sacrey says the APSI has excellent potential to aid physicians in early diagnosis.

Parents may have a hard time pinpointing what's twigging their sense that something's not on track in their child's development, according to Dr. Sacrey. "So what's great about the APSI is it guides them to give physicians concrete information," she says. "This way they can be referred to the right services early on."



Younger brothers and sisters of children with autism are more likely to develop the condition than children with typically developing siblings.

The APSI is cost-effective, and a time saver—Dr. Sacrey says it only takes five to 10 minutes to fill out.

It also appeals to community partners: TARGet Kids!, a community pediatric research network in Toronto, is excited to work with our researchers to assess how families and clinicians feel about very early screening for autism, and evaluate the feasibility of using the parent screen in clinical practice.

theme 2

Supporting Social Skills and Self-Regulation

"Children with neurodisabilities need social skills and behavioural training, as well as strategies for self-regulation of emotions and anxiety."

From: Stakeholder Engagement Activity Report 2017 | Kids Brain Health Network KT Core

Five Network projects engage community-based partners in direct work with kids and families to develop the capacities and resilience parents tell us their children need most in order to thrive.



Understanding and support are key to helping kids learn integral life skills

Everywhere they go, children and youth with neurodisabilities face unseen challenges that can show up in the form of outbursts, and difficulties with anxiety and social interactions.

Part of what underpins these outcomes is trouble with executive functioning: the lack of ability to pay attention, organize and plan, to initiate tasks and stay focused on them. Lack of social skills and emotional regulation are also involved. Impairments in these areas can represent major barriers to success in school, employment and satisfying relationships.

"In every one of Kids Brain Health Network's family engagement activities, parents have talked about the importance of executive functioning, social skills and self-regulation," says Scientific Director Dan Goldowitz, "and we're responding." The Network is funding five research projects evaluating programs that work directly with families and children to develop these integral life skills.

Interventions change life for kids and families

ASD

Secret Agent Society - Operation Regulation and MyMind programs provide community-based agencies with new ways to support pre-teens and young adults with autism

There is a need for understanding and supporting youth who have difficulties with involuntary behaviours, according to Dr. Jonathan Weiss, who is leading two research initiatives aimed at equipping pre-teens and adolescents with autism with the tools to manage their behaviour and emotions themselves.

"The more comfortable people get with who they are, and with being able to accept in a very positive way their difficulties and challenges, and identify what really matters to them, the better they are at becoming goaldirected," says Dr. Weiss.

This is the thinking behind MYmind, a mindfulness-based intervention for teens with autism spectrum disorder (ASD) and their parents, which helped provide both groups with strategies for managing stressful situations with heightened awareness.

The intervention showed success in building teens' social communication skills and reciprocity, and also helped with repetitive behaviours and perseveration. For parents, the training enabled them to approach their child's difficult behaviour with understanding and composure.

"My son is meeting me halfway through and we talk about things," remarks one parent in the program, "and that makes all the difference in the world to me."

With the pilot study complete, positive feedback from families has led the Geneva Centre for Autism, Lake Ridge Community Support Services*, and other organizations to implement mindfulness activities like MYmind for the autism community. Dr. Weiss and his team, however, are moving beyond the intervention.

"We need to be very careful about rushing to the community with the newest and greatest thing," says Dr. Weiss. Instead, he is acting on stakeholder input that urged him to evaluate existing tools and products to give families unbiased advice about what works and doesn't, as well as the flexibility to adapt to their needs.



EMOTION REGULATION CADETS

One such product is the multi-component Secret Agent Society - Operation Regulation program meant to improve emotion regulation abilities in children with autism, aged 8-12 years. Dr. Weiss has been evaluating this cognitive behavioural therapy based program using funding from his five-year position as Chair in Autism Spectrum Disorders Treatment and Care that wraps up this year. Kids Brain Health was one of the chair funders.

Training is delivered one on one, with a therapist, parent and child working together in the clinic. The Secret Agent Society - Operation Regulation (SAS-OR) program helps youth with autism cope with their emotions and handle day-to-day stressors by teaching tools and strategies. Children learn these strategies through numerous spy-themed activities like an emotion-focused computer game, cue cards, session games, and parent and teacher handouts.

So far, more than 60 youths have participated, and as a group, show significant improvements in their capacity to regulate their emotions.

"The progress we made in the span of what I would call six months—night and day," says one parent. The program has also shown indirect benefits to parents in terms of their own ability to regulate their own emotions and more calmly approach their child.

*Learn more about our partners

Geneva Centre for Autism https://www.autism.net/ Lake Ridge Community Support Services www.lrcss.com/

ASD Starting young, before the child enters school

Social ABC's intervention offered through a community partner promotes development of social and language skills

Between 40-70% of children and youth with a neurodisability face mental health issues such as depression, social anxiety, or obsessive compulsive disorder. Early diagnosis and intervention can improve outcomes in these areas by teaching valuable social and selfregulation skills before the child enters school.

"Even when parents are very vigilant, their child might not get assessed until they are three or four years old," says Dr. Jessica Brian, co-developer of the Social ABC's, a parent-facilitated intervention program. "We know that with ASD earlier is better, so this was the context in which we developed this toddler intervention."

Social ABC's aims to develop social and language skills in toddlers and young children showing signs of autism or atypical communication skills. With guidance from trained coaches, parents learn to promote these capacities through everyday activities and interactions. "The program is just fabulous," says one parent participant, whose son "has made leaps and bounds since starting it."

Social ABC's successes in a multi-site feasibility study* and in Humber College daycare settings have prompted a community extension pilot in Ontario. Offered in partnership with Hamilton Health**, the pilot may lead to wider offering of Social ABC's throughout the province. Two manuals have been developed to support further work, one for parents, and a second one for coaches.

"Every community has different resources, but I think this program would be transferrable to any community," adds Dr. Brian. "Parent-mediated interventions are less resource-intensive and therefore less costly. Social ABC's provides an opportunity to work with kids who don't yet have a formal diagnosis when it's suspected they will go on and develop ASD."



*Autism Research. 2016 Aug;9(8):899-912. The Social ABCs caregiver-mediated intervention for toddlers with autism spectrum disorder: Feasibility, acceptability, and evidence of promise from a multisite study.

****Learn More about our partner** Hamilton Health Sciences www.hamiltonhealthsciences.ca

FASD Bridging barriers to service

Parent support program for challenging behaviour adapted at the request of First Nations community partner



Strongest Families FASD also relies on coaches supporting parents who deliver the intervention to their child with a significant difference: the customized behavioural program is provided online.

Structured as a series of modules, each teaching a skill, Strongest Families FASD enables parents to focus on a particular behavioural challenge, or on improving their approach to managing the behaviour. Parents of children with FASD, aged 3-12, are matched with individual coaches who support them in working through the program and implementing new skills in their daily lives.

Much of the online intervention is based in building supportive and encouraging relationships between the parent and child, which can be strained when families are overwhelmed and children are acting out.

"It becomes very easy as a parent to focus on the negatives and forget that every child has things they're good at, and is doing things on a daily basis that in fact they should be rewarded and complimented for," says Dr. James Reynolds, deputy scientific director of KBHN, and co-lead of the FASD research project. "It's turning the perception around... to a positive one." Dr. Christopher Mushquash believes this approach to be especially valuable in the context of First Nations communities. A culturally-and contextuallyappropriate adaptation of the program is rolling out to First Nations families in clinical trials to bridge service barriers in remote communities.

"The idea that we're providing a service that focuses on positive parenting in supporting difficulties is very congruent with the values of the community that we've partnered with," says Dr. Mushquash, principal investigator of the adaptation.

By the spring of 2018, Dr. Reynolds anticipates that Dr. Mushquash and partner Dilico Anishinabek Family Care* will have enrolled more than 150 families in the program overall, adding the adaptation to the repertoire of clinical services available through the Strongest Families Institute.

Learn more about our partner Dilico Anishnabek Family Care http://www.dilico.com/

Getting the ball rolling, for parents too

Evaluating the potential of existing physical activity programs as support for child and family

Another project that rests on parent engagement and partner collaboration is evaluating physical activity programs [PAPs] as comprehensive treatment options for children with neurodisabilities. Led by Dr. Jean-Paul Collet, the team has found that attending PAPs helps children and youth develop executive functioning capacity that translates into better quality of life. The effects on the entire family are transformative.

"I think people often tend to forget that when you have a child who is not neurotypical [developing typically] it is very hard to raise them," says one parent whose child participates in a PAP. "All those books you read about parenting do not apply. Some days you feel very alone."

Physical activity programs like Empowering Steps Movement Therapy, and programs offered by Canucks Autism Network, Special Olympics BC, and other organizations have seen success in improving the self-regulation and confidence of children with neurodevelopmental conditions. "We are grateful for [the program] because it gives him something to look forward to and a sense of accomplishment," says one family whose son takes part in a Special Olympics program. "It makes him—and us—happy."

PAPs have also provided judgement-free spaces for parents to connect and build meaningful, supportive relationships that they may not otherwise have with parents of neurotypical children.

"Talking to other parents and seeing your child out there, you get comfort, and you can say your child is playing hockey, soccer or swimming," says one parent. "Now we all cheer I am a soccer mom!"

With an evidence base and subsequent funding, Dr. Collet hopes to see programs like these reach more families across Canada.



Learn more about our partners Empowering Steps Movement Therapy Program https://clubaviva.ca/

BC Special Olympics http://www.specialolympics.bc.ca/

theme 3

Schools and Children with Neurodisabilities

"The Canadian school system does not promote success for children with neurodisabilities. In-depth training should be required for anyone in school settings that interacts with children with neurodevelopmental conditions."

From: Stakeholder Engagement Activity Report 2017 | Kids Brain Health Network KT Core

A pioneering outreach and education program funded by Kids Brain Health Network and partners supports families and works with educators as part of a wide-reaching mandate, because improving school experiences is a top priority for the parents we—and they—engage.



FASD

The right school and the right support make all the difference

The Fetal Alcohol Resource Program supports families, schools and educators in training

Joyce Hamelin was at her wits' end. Her 12-year-old son was in a behavioural intervention class where he frequently flipped desks, tore things off the wall, and ran out of the classroom. His explosions were escalating, and one day he climbed onto the roof of the school, refusing to come down.

"If you ask Jayden he will tell you that school is just torture for him," says Joyce, who explains that he's been approached the wrong way his entire life. While he's never had problems making friends, Jayden needs a lot of time to process information and isn't consistent in his functioning from day to day.

"He might do well on a math question one day and then can't do a similar question the next day because he can't remember how, and the school sees this as defiance," says Joyce. "This just raises his frustration level and lowers his self-esteem." That's when she heard about the Fetal Alcohol Resource Program (FARP), an initiative led by Citizen Advocacy Ottawa* and supported by Kids Brain Health, that provides knowledge and resources to people living with FASD. "I felt like 1,000 bricks were lifted off my shoulders," says Joyce.

FASD AND THE EDUCATION SYSTEM

"The education concerns just come up over and over again from parents," says Nancy Lockwood, FARP program manager. "Too often [the school board] is saying it's a behaviour issue and a learning disability, but they're not understanding that the behaviour issues are just a symptom of the brain injury." *continued on next page >*

After two years of badgering professionals for testing, Jayden was diagnosed with fetal alcohol spectrum disorder (FASD) last year. He is one of 250,000 Canadian children with FASD battling against an uncomprehending education system that drives them to despair. The day Jayden climbed onto the school roof, Joyce says she was desperate for help and called Children's Aid.



*Learn More about our partner Citizen Advocacy Ottawa www.citizenadvocacy.org/

FASD The right school and the right support make all the difference continued



Lockwood says some of the biggest issues with the education system are that students with FASD need more time to process information and often need things repeated—something most teachers feel they don't have time to do. Large class sizes cause distractions for students with FASD, and there often aren't enough educational assistants to provide extra help. It has been difficult for FARP to infiltrate the school system, she adds, likely because many educators don't realize how many students have FASD, and training teachers requires substitute teachers to be brought in.

Based on the guidance she got from FARP, Joyce has decided to change schools and transition her son into a regular classroom starting in September. The new school has been trained by the FARP team, and has been very proactive in promoting Jayden's success by having him come in to meet his teacher and choose his desk. "One of the things I was most impressed with was that [FARP] let me express my feelings and then they backed me up with evidence-based research that put other professionals in a position where they had to listen to my concerns," says Joyce.

THE ROLE OF THE FETAL ALCOHOL RESOURCE PROGRAM (FARP)

The program's main goal is to play a navigator role. When someone reaches out to FARP, the team will guide them to programs in the community. "In the future, I hope we can have more funding and staff so we can offer more individualized support and navigation for families like we did for Joyce," says Lockwood.

FARP has a database—which continues to be updated containing resources and agencies in the Ottawa area that are able to help families living with FASD. The FARP team will often train people working at these agencies to ensure they are providing the best possible services to individuals and families living with FASD.

"We recently had a family contact us because they had to find emergency housing for their adult child, and within five minutes we were able to give them five good options using our database," reflects Lockwood.

To date, the program has trained over 1,000 frontline workers across many sectors including justice, health and education. FARP has taken many steps to facilitate a positive relationship with school boards and families living with FASD, including running workshops and training session.

"[Joyce's story] is a positive example of how by us being there to help advocate for her and her family, we have been able to find a better fit for her son," says Lockwood.

FARP has also trained teaching candidates on FASD, which has elicited a very positive response, with one student saying the training will allow them to, "keep what I learned in mind going forward to help recognize FASD and how to handle it."

NEXT STEPS FOR FARP

Using the existing model in Ottawa, KBHN is now working with partners in Edmonton, Vancouver, and Whitehorse to create and operationalize similar programs in these areas. By addressing the specific needs of each community, the goal is to develop programs that help families living with neurodevelopmental disabilities such as FASD navigate available resources in each of these three cities.

FARP continues to seek out partnerships and broaden their reach by offering workshops, conferences, and campaigns to raise awareness. They are also working towards offering services in French. Recently, the team has been working with the Children's Hospital of Eastern Ontario to determine how a functioning FASD diagnostic clinic could be implemented in Ottawa—a region of one million people that currently has no multidisciplinary approach to diagnosis. Other critical partners include the University of Ottawa and the Children's Aid Society of Ottawa.

"This program has already achieved far more than our most optimistic estimation of what it could do," says Dr. Reynolds, Deputy Scientific Director for KBHN and FARP advisory committee member. "I think it's a fantastic example of what happens when a group of agencies and individuals come together in a partnership with common and shared goals."





Transitions

"We need continuity in services at key times and transition points and acknowledgement of the life-long nature of these conditions."

From: Stakeholder Engagement Activity Report 2017 | Kids Brain Health Network KT Core

Kids Brain Health projects and a research chair supported by the Network study and strive to support transitions from toddler years through young adulthood and beyond, because families tell us the system is failing to maximize the potential of people with neurodisabilities.



Working to understand and ease the stress of transitions

Social Determinants of Health, Neuroethics researchers, and autism chair focus on supporting individuals and system-level change to support transitions.

It starts with the meltdown that follows an errand-packed day in and out of the car seat, or leaving the play area at the park at dinnertime. These may be transient events in the life of a typical child, but they're daily fare for parents raising children with neurodisabilities, whose lives revolve around planning and adaptation.

Before Kids Brain Health Network researchers began looking closely at the lived experience of transition, research in this area tended to focus on what is typically described as "the abyss" beyond high school graduation, when access to support services and the structure and predictability of educational settings both come to an end. There are many other transitions that also happen along the way, beginning when it's first recognized that there's something different about the way a child is developing, and the journey involved in securing services and supports at the time of diagnosis, followed by the move to preschool, entry to elementary school, and entry to high school.





"What parents tell us is that every year is a transition," says Dr. Lucyna Lach, co-lead of Kids Brain Health Network's Social Determinants of Health (SDOH) research group. "As a child moves from grade to grade, the players change, or if the child changes schools—there are the big transitions we think about that are documented in the literature, and then there are other ones that occur on a year-to-year basis, and even day-to-day basis."

Understanding how families raising children with neurodisabilities experience transitions is a major focus for the SDOH team. Their goal is to mobilize evidence they gather through listening to families and exploring big datasets that looks at the contexts in which these families live. Their partners in this work are plentiful: healthcare, education, justice, law enforcement, corrections, child welfare, and social services, all of whom play a role in supporting children and families. *continued on next page >*

Working to understand and ease the stress of transitions continued

"We've engaged more than 50 families in Calgary and Montreal to tell us about their experiences of accessing supports during these pivotal periods," adds Dr. Lach.

CP+

NEEDS VARY WITH TIME

"Meanwhile, the nature of support that families and children need will vary across the lifepath," says Dr. David Nicholas, SDOH co-lead. "We think about transitions as being solely temporal, but they might be more situational. They might involve an adjustment from living with a difference to receiving a diagnosis, and suddenly having one's area of difference be problematized, or experiencing a change in family membership; or transition to living life in a new community with a diverse and unfamiliar array of services to navigate."

Children are often diagnosed at a specialty centre, but typically receive services in the broader community, where there's a disconnect between the child's needs and what's available. There are also transitions within and between service systems where access is either denied or at best, delayed. For example, children with neurodisabilities who also have mental health issues may be bounced between the health and social service system to the mental health system. "These systems can be very siloed, and only available in specific locales," adds Dr. Nicholas.

The discontinuities that come with adolescence are keenly felt in health care. Youths exit the pediatric realm, and suddenly confront the silo of the adult system. Previous interviews with young adults with cerebral palsy sensitized Dr. Éric Racine, co-lead of the Network's Neuroethics group to the experiences of youth at this transition. "What we heard from youths was that they were very much offended that clinicians would not interact with them directly [in the adult system]," he said.

continued on next page >



It turns out that young people are very comfortable with a shared decision-making model...that goes against the common wisdom of needing to be seen as separate from their parents.



"One of the trends is to make independence in life one of the key goals," adds Dr. Racine. "In Quebec, official legislation allows children 14+ to make some medical decisions alone. This sends a signal about how much we would need to prepare children for this, and often, they're not even comfortable, engaging by themselves. The power disparity is so huge between clinicians and teens.

"Something that's coming from the data we've collected is that the goal of independence may not be necessarily important to the youths themselves," adds Dr. Racine. It turns out that young people are very comfortable with a shared decision-making model, even as adults. That goes against the common wisdom of youth needing to be seen as separate from their parents. It's not necessarily applicable for all youth with neurodisabilities, and not necessarily important to the youths themselves."

The data, combined with the results of a scoping review of best practices in transition care, are providing the foundation for a novel ethics intervention to support health care transitions for youth with a neurodisability: a personalized transition program that operationalizes tailoring plans to take into account the needs and preferences of the child or youth.

MOVING FROM INSIGHT TO INTERVENTION

Dr. Racine is collaborating on the project with KBHN post-doctoral fellow Aline Bogossian, who did her doctoral work in social work with Dr. Lach. "There's a theoretical intervention in our heads right now," he says. "It will emerge out of talking to youth with disabilities, their caregivers and their clinicians, who are stuck in this push-pull between overwrapping a kid and allowing them to fulfill their abilities, and not providing them with the ability to accomplish what they can, by failing to provide them with a safety net. Aline will be negotiating that push-pull, documenting how it manifests."

Doctors, who will be key partners in translating the findings into impacts in clinical settings, say the findings resonate with what they experience, says Bogossian. Members of a national interdisciplinary task force are already involved, identifying established transition programs across Canada that might welcome an ethical perspective on their offerings.



Working to understand and ease the stress of transitions continued

ASD

AUTISM CHAIR SUPPORTS INDIVIDUAL AND SYSTEM LEVEL CHANGES AROUND TRANSITIONS

"I think when families say that they have challenges around transitions, especially around specific ages, that's the canary in the coal mine. That's an indication of how flexible our systems are in supporting people who have a chronic disability," says Dr. Jonathan Weiss, lead of the Network's MYmind project, a mindfulness meditation intervention aimed at teens with autism and their parents.

Transitions were one of the priorities identified in the stakeholder consultations Dr Weiss undertook as part of a five-year Chair in Autism Spectrum Disorders Treatment and Care Research funded by Kids Brain Health Network and partner organizations. "We've published studies that documented the kinds of needs people with autism have at different life stages in Canada. Transitions are a major stressor, particularly in autism," says Weiss. "We've documented the needs people with autism have at different life stages in Canada. Transitions are a particular stressor." - Dr. Jonathan Weiss

"Both the MYmind and Secret Agent Society: Operation Regulation projects (see story page 12) are about helping youth from pre-teenage to young adulthood be okay with doing things that are hard for them. That often involves change. Neither of those interventions focus on changing the system of care, but they make a difference in an individual's being okay with change and transition.



Transition means changing into something. Moving towards something. So you have to have the *something* piece addressed as well for successful transition."

Weiss describes the Chair as being a great mechanism for helping mobilize research to push change at the system level in collaboration with partners. A successful national needs assessment conducted with the Canadian Autism Spectrum Disorders Alliance "provided findings that enabled the alliance to speak more strongly and effectively to governments about the needs of the autism community across Canada," says Weiss. "This kind of thing informs the decisions that policymakers make to further improve the kinds of supports that exist in the system."

The Chair also helped inform how Autism Speaks Canada apportioned its community building grants across the country. "They used the priority needs that were identified in our research as the key areas of focus in their funding calls," adds Weiss. "As a result of that, we've seen grassroots initiatives across the country develop with those directions in mind: social inclusion, transition supports, vocational supports, housing...Those are two very direct links of what this research chair undertook in terms of shaping systems of care in Canada."



Dr. Jonathan Weiss hosted the 2016 TedX YorkU Salon.

SYSTEM NAVIGATION AS A WAY OF SUPPORTING CONTINUITY IN TRANSITIONS

"We really need to think carefully around an integrated and coordinated system of care so people can move from diagnosis to services, and as needed, receive different levels of care and prevention in the community, as well as more acute and crisis services if required," reflects Dr. David Nicholas of the Social Determinants of Health research group.

"Insufficiency of services is an important and challenging issue," adds Nicholas. "When I think about transition and system navigation, the two notions go hand in hand. In the next phase of our work with Kids Brain Health Network, we're moving into system navigation. It can be a real challenge to get parents current information in terms of accessing the right service at the right time. The path of getting what is needed for their child, or for themselves as a family may be convoluted. There can be formidable hoops to jump through and much to orchestrate—and in some cases, pay for —as well as tremendous inequities based on locale and other barriers.

"The more we bring this to light," says Dr. Nicholas, "the better the project is doing in raising awareness toward positive action and change."

Learn more about our partner Canadian Autism Disorders Alliance www.casda.ca/

ASD

CP+

Social determinants expertise sought for post-diagnostic system navigation in Quebec

Support from Kids Brain Health Network and other partners has enabled the SDOH team to contribute expertise to a Miriam Foundation project involving transition and access to care.

The See Things My Way Centre for Innovation in Autism and Intellectual Disabilities at McGill University has launched two pilot projects to assist families with pre-school aged children undergoing diagnosis of autism, generalized developmental disorder, and/or intellectual disability.

In the first, the SDOH team is working with the Centre's clinical team to document how their approach before, during and just after diagnosis is implemented and what difference it makes. "They know that they're doing a great job, and in order to let others know about it and replicate it, they need to document what it is that they are doing," says Dr. Lucy Lach, co-lead of the SDOH team. "Understanding successful ingredients is key to this process, and the overall objective of the pilot: decreasing the waitlist for diagnosis in Montreal."

The second pilot involves improved access to intervenants pivots—caseworkers who serve as navigators in the public health and social service system, working with families to support them in coming to terms with their child's diagnosis and adjusting their parent style to support optimal development. The intervenants pivots are also charged with ensuring follow-through on postdiagnosis treatment and intervention plans.

"We have found that the support that families receive is very uneven within and across different sites in the city of Montreal," says Dr. Lach. The objective of the second pilot is to even things out. "As care is handed over from the See Things My Way clinical team to the intervenant pivot, it should be seamless as the intervenant pivot becomes the 'go-to' person for the family. Best practice guidelines are needed to ensure that minimum standards are met."

Transitions-related work is also proceeding in other regions. A Kids Brain Health Network team is working together with a range of partners in Alberta, British Columbia and the Yukon to improve navigation resources for families. This initiative, in its infancy, is inviting important discussions about what is working and what needs to work better to optimally support families as they seek to access support that they and their children need.



Learn more about our partner See Things My Way Centre for Innovation in Autism and Intellectual Disabilities www.seethingsmyway.org/

theme 5

Equity and Access across Disorders and Geography

"We need more equity in funding across different neurodevelopmental conditions; reduced barriers to diagnosis and increased access to treatment; more resources, and more efficient use of existing resources to expand a system that recognizes the challenges involved in complex care."

From: Stakeholder Engagement Activity Report 2017 | Kids Brain Health Network KT Core



Network researchers provide evidence and engage with policymakers to promote equity and reduce barriers

Social Determinants of Health and Knowledge Translation researchers work with both federal and provincial governments alongside community partners.

For many years, families in Pinaymootang, Manitoba had no option but to drive for hours to seek treatment for their children with neurodisabilities.

The remote First Nation of 2,800, located 220 km northwest of Winnipeg decided to change that reality, and applied for federal funding to develop a program that serves Pinaymootang children with complex needs at home.

Launched in 2015, My Child, My Heart supports nearly 30 children with a variety of neurodevelopmental conditions on reserve. "[The program] was created to ensure that the community's children receive the same level of care as children living in urban settings," Pinaymootang Health Centre Executive Director Gwen Traverse told CBC in a recent interview.

Together with parents, child development workers identify what the child's and family's needs are, and make a plan to help them to achieve those goals. Goals range from obtaining respite care to assisting with physiotherapy exercises, to teaching sign language.

"The services kids have access to off reserve are very different than on reserve," agrees Dr. Lucyna Lach, colead of KBHN's Social Determinants of Health research group. Dr. Lach has worked with My Child, My Heart to put in place tools for evaluating the effectiveness of the program, which are important for validation and replication of the approach.



A NEED FOR SENSITIVITY ABOUT BASIC RIGHTS

My Child, My Heart's successes have attracted the interest of other First Nations and policymakers, who are looking to replicate its model of community-based care. Funding for the program comes through the federal commitment of \$382.5 Million over three years to implement Jordan's Principle, a child-first agreement meant to ensure First Nations children don't experience denials, delays, or disruptions of services ordinarily available to other children due to jurisdictional disputes.

Jordan's Principle, rooted in reconciliation and child rights, was born out of sorrow: Jordan River Anderson, a First Nations child from Norway House Cree Nation in Manitoba, died at the age of five in the hospital, while the federal and provincial governments were locked in disagreement about who should pay for his care.



Jordan River Anderson photo retrieved from winnipeg.ctvnews.ca

Ethnicity, location and lack of legal precedent establishing fiduciary responsibility for a child's care constitute significant barriers to services for First Nations families across Canada. So does diagnosis.

Where you live, what you make and what your child has affects access among non-Aboriginal families as well. "Some disabilities have been funded in ways that others have not," says Dr. Lach. "For some families, a diagnosis of autism is the ticket to receiving treatment and support, while a diagnosis of FASD is not, and this is problematic. We have to move in the direction of a less diagnostic and categorical approach to one that is focused on addressing needs and functional limitations instead of labels."

"Service delivery is not one size fits all," agrees David Nicholas, co-lead with Dr. Lach of the Network's Social Determinants of Health research group. "Communities face barriers in a very poignant way that needs to be amplified and addressed. There needs to be a sensitivity that basic rights are being neglected."



Quantification as an argument for access

Social Determinants of Health researchers' prevalence research sets important benchmark.

Articulation of access as a legal, rights-based issue is one way policy change has been stimulated.

Another approach is quantification. Governments and communities alike lack the advantage of knowing how many children are affected by neurodisabilities. The absence of a benchmark acts as yet another barrier.

Using linked administrative health data provided through Population Data BC in British Columbia, Dr. Lach and partners from Statistics Canada recently identified that about 8% of children aged 6-10 years, who were continuously registered with the British Columbia Medical Services Plan had a diagnosis reflecting a neurodisability.

"Establishing the prevalence rate of children with neurodisabilities is important because it renders something that was previously invisible, visible," says Dr. Lach. Prevalence rates are critical for resource planning for income support, health, education and social services—big ticket items for government. They also enable comparisons with other countries, and open the door to investigation of a variety of contributing factors, including social, biological and environmental causes.

"Dr. Lach's work on prevalence is truly foundational," says Tom Philpott, executive director of Kids Brain Health Network. "It's a key underpinning of evidencebased policy that accurately reflects the needs of the population. People are often surprised when they learn of the absence of fundamental data to inform policymakers. This must change." About 8% of children in British Columbia have a diagnosed neurodisability



So how do families, researchers, service delivery partners and policymakers leverage this knowledge and work together to increase equity? "No one group has the solution on their own," adds Dr. Lach. "Things improve when they work together. When the focus returns to the rights of the child, these partners are able to create solutions."

Promoting rights based approaches nationally and internationally

Network KT researcher carries evidence from participation research and stakeholder engagement into policy encounters.

With her background as an occupational therapist focusing on access and participation opportunities for children with cerebral palsy and other mobility issues, and an interest in policy engagement, Dr. Keiko Shikako-Thomas has carved out a niche. Her work on the KBHNfunded Jooay App that connects families to local adapted leisure activities, consultation with a wide range of stakeholders across several provinces and exploration of rights-based approaches in disability translated into a well-received policy brief introduced into public consultations on the federal Accessibility Act. Dr. Shikako-Thomas' ongoing interaction with the Federal Minister of Sport and Persons with Disabilities and the Office for Disability Issues brought visibility when a group of civil society organizations (non-profits) sought a pediatric perspective for its representation to the UN Commission on the Rights of the Person with Disabilities.

"In 2016 in Geneva, we were asked why there was nothing about the rights of children with disabilities in our Civil Societies report," says Steven Estey, lead of the Canadian Civil Societies Delegation.* "In truth, we'd never really thought about it before. We came back to Canada to identify a national organization looking specifically at the rights of children with disabilities. [KBHN's Dr. Shikako-Thomas] and the research she was doing were best placed to engage in the work around children in the 2017 Shadow Report."

As the voice for children within the Shadow Report and on the committee, Shikako-Thomas brought forward a characterization of evidence on the status of children with disabilities. This collaborative effort of four KBHN researchers was included alongside the report submitted by the Government of Canada to the UN's evaluation **Dr. Keiko Shikako-Thomas** converses with **The Hon. Carla Qualtrough,** (right) then Minister of Sport and Persons with Disabilities



of Canadian implementation of the Convention on the Rights of Persons with Disabilities (CRPD). "A seat for children at the convention table sets a new precedent," says Dr. Shikako-Thomas, one where their voices and unique set of challenges experienced by children, youth, and their families may help shape future expectations and benchmarks set for Canada.

*Learn more about our partners the Canadian Civil Societies Delegation http://www.ccdonline.ca/en/blog/Frank-Folino-31March2016

Informing research and policy with a child rights perspective—the work ahead

Shaping Network strategy

Improving outcomes for children with neurodisabilities means bringing families into an equation involving government and policymaking, says KBHN Executive Director Tom Philpott. "Having researchers, governments, partner organizations, and families defining together the problems we need to solve is definitely the way forward. And within government, this requires cross-ministerial efforts."

Involving families who aren't yet represented in these conversations is critical, reflects Dr. Shikako-Thomas. Researchers often engage with families that are already involved, or are seasoned advocates.

"We can empower other groups, representing rare diseases or less common developmental diagnoses by providing evidence, by getting them organized through research projects, and by providing access to information so they have the tools to advocate successfully for their child and the services they need—and have a right—to access," she adds.

Dr. Lach agrees. "When you create a groundswell about rights at the grassroots level, then parents are willing to invoke that language."

Ultimately, adds Dr. Shikako-Thomas, families most accurately identify the challenges policy should seek to overcome. "We need to consider that in our strategy and methodology for stakeholders. It's a big challenge but working with the hard-toreach populations and how we get their voices represented is really the next frontier."

The Civil Societies Delegation and Dr. Shikako-Thomas are joined by the Hon. Senator Jim Munson, then Minister of Sport and Disability Carla Qualtrough, youth council delegates and other Canadian dignitaries at the 10th meeting of the Conference of States Parties to the UN Convention of the Rights of Persons with Disabilities in New York City.



research & training program update

Network research and training program immerses trainees in stakeholder perspectives on research

Historically, graduate and post-doctoral training in neuroscience hasn't fostered the skills needed to assess the voiced needs of the people most affected by their research findings.

Enter the Kids Brain Health Network Research and Training program. Overseen by a dynamic committee of top clinician/researchers, the Network's program has been instrumental in preparing new researchers to enter the neurodevelopmental community. KBHN trainees are presented with diverse opportunities designed to prepare them for the cross-disciplinary realities of 21st Century work in academia and industry, including immersion in the perspectives of children with neurodisabilities, and those of their parents and the organizations that serve them.

"[Teaching stakeholder engagement] is critically important for the future generations of trainees/ scientists," reflects Dr. Jill Zwicker, a former Network trainee who is now a member of KBHN's Research and Training Committee. "Patient engagement and involvement from the beginning are now expected for research studies, so it is important for our trainees to gain knowledge and skills in this area."

CULTIVATING CRITICAL SKILLS THAT AREN'T TYPICALLY ON OFFER IN GRADUATE TRAINING

"In this era of patient-oriented research and medicine, a better understanding of the needs and interactions with key stakeholders—including patients and families, front-line caregivers, and even policy makers—is critical to make research relevant and impactful beyond academia," agrees Research and Training Manager Dr. Doug Swanson. "While this has not been a main aspect of graduate education in the past, the KBHN recognizes that this is a vital piece of a trainee's development toward becoming a successful researcher. So effective engagement became a new and important learning objective for the training program, which we incorporated in the design of NeuroDevNet 102."

NeuroDevNet 102, a webinar-based course held in early 2016 prior to the rebranding of the Network as Kids Brain Health, introduced many young researchers to the importance of stakeholder priorities for the first time. They delved in, breaking into groups representing various partners in the research process, and explored what they knew and what they could learn from the Web. The students then queried course presenters from the perspective in which they'd immersed, and represented their respective roles in live discussions and an online class forum.

JOINT FELLOWS THE BEST AND THE BRIGHTEST

Most of the participants in NeuroDevNet 102 were also awardees of the inaugural Brain Canada-KBHN* collaborative Fellowship Program.

"This joint fellowship was designed to bring together an exceptional and diverse group of trainees focused on different aspects of brain development and provide them with a sound foundation in developmental disorder research," says Dr. Swan. "The hope is that these trainees represent the best and brightest, with high potential to become leaders in their field as well as highly collaborative researchers that will stay engaged in the Network and in the research and stakeholder communities."

*Learn more about our partner Brain Canada www.braincanada.ca/

meet our fellows



Trainee: Sarah Raza, PhD Student, University of Alberta

Fellowship Project:

The role of attention control and emotional regulation in the emergence of autism spectrum disorder (ASD): Identifying early markers of ASD in at-risk infants

Project Description:

My research focuses on early development in autism spectrum disorder (ASD), with the goal of identifying behavioral and physiological markers in at-risk infants. I am interested in the role early attention and emotional regulation play in the emergence of autism, and anticipate that my research will shed light on the initial signs of ASD and provide insight into its diversity. Identifying these risk markers may advance early detection and diagnosis, as well as inform new avenues for intervention that may reduce or even prevent clinical expression of ASD.

Reflections on KBHN Trainee Program:

Coming from a basic science background, my previous graduate training did not emphasize the importance of stakeholder perspectives and knowledge translation. NDN 102 not only enhanced my knowledge of the emerging issues in the field of neurodevelopmental disorders, but also broadened my understanding of the roles various stakeholders may have in research and health practice. I now have a shared understanding of the issues and concerns parents and/or children may possess when going through the process of autism diagnosis, as well as a greater ability to empathize and facilitate dialogue with these families.



Trainee: Graham Little, PhD Student, University of Alberta

Fellowship Project:

Combined analysis of brain magnetic resonance images towards patient specific diagnosis of fetal alcohol spectrum disorder

Project Description:

My current focus is on building computer software that can identify altered brain development patterns in fetal alcohol spectrum disorder (FASD) using brain images. The aim is to create an objective tool that can detect atypical brain development and potentially monitor the effects of interventions. My goal is to be able to identify a brain signature of FASD that can help in diagnosis of prenatal exposure to alcohol, making it easier to provide the unique help and resources affected children and their families need.

Reflections on KBHN Trainee Program:

NeuroDevNet 102 helped me understand the competing and/or mutual stakeholder goals that can shape the types of research conducted in our scientific communities. Most importantly, the course gave me insight into the wide range of individuals impacted at some level by neurodevelopmental disorders.



Trainee: Emily Bremer, PhD Student, McMaster University

Fellowship Project:

Movement skills, physical health, and behaviour in children with autism spectrum disorder

Project Description:

My research looks at the relationships between movement skill, physical activity, fitness, health, and behaviour in children with and without neurodevelopmental disorders, particularly autism spectrum disorder (ASD). The project also explores how physical activity and exercise can be used as an intervention for children in order to improve their physical, mental, and behavioural well-being. Ultimately, I hope my research will provide children with the necessary movement skills and knowledge to be physically active and fit, as physical activity can be leveraged to improve behavioural and cognitive outcomes.

Reflections on KBHN Trainee Program:

I am a big believer in doing research that makes a difference in the community, whether that be through wide-spread adoption of new interventions, or policy changes. I know that in order for this to happen, stakeholders need to be consulted along the way and should not simply be seen as end-users. The program definitely helped me think about the fact that different stakeholders may have different interests in the same project, which can be a challenge to address but is ultimately important for later uptake.



Trainee:

Regula Neuenschwander, PhD, Postdoctoral Fellow, Child and Family Research Institute

Fellowship Project:

Developmental origins of stress and self regulation and implications for interventions to improve childhood behaviour

Project Description:

My research aims to explore how exposure to stress during pregnancy affects children's development specifically in relation to children whose mothers were depressed during pregnancy. I am examining whether or not these children have problems later on with coping with stressful situations, and if this in turn leads to difficulties in other domains such as the thinking process or mental health in general. My hope is that this project will shed light on pathways through which exposure to prenatal stress shapes developmental health and risks—the knowledge of which can be used to design interventions for children and mothers suffering from depression.

Reflections on KBHN Trainee Program:

My understanding of the role of stakeholders in conducting research has been shaped tremendously by this program! I was especially intrigued by the idea of participatory research and collaborative partnerships (community-research) that was introduced in the course. I learnt a lot about knowledge translation and the need to engage with knowledge users, target audiences, and stakeholders in order to ask the right/ crucial research questions. Ultimately for me, as a basic researcher, that means really thinking beyond a publication.

financial statements

for the years ended March 31, 2017 and 2016



Independent Auditor's Report

To the Directors of Kids Brain Health Network Inc. (formerly Neurodevelopment Network Inc.)

We have audited the accompanying financial statements of Kids Brain Health Network Inc. (formerly Neurodevelopment Network Inc.), which comprise the statements of financial position as at March 31, 2017 and 2016, the statements of operations and changes in net assets and of cash flows for the years then ended, and a summary of significant accounting policies and other explanatory information.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with Canadian Accounting Standards for Not-for-Profit Organizations, and for such internal control as management determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with Canadian generally accepted auditing standards. Those standards require that we comply with ethical requirements and plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

In our opinion, the financial statements present fairly, in all material respects, the financial position of Kids Brain Health Network Inc. (formerly Neurodevelopment Network Inc.) as at March 31, 2017 and 2016, and its financial performance and its cash flows for the years then ended, in accordance with Canadian Accounting Standards for Not-for-Profit Organizations.

Hay + Watson

Chartered Professional Accountants Vancouver. British Columbia July 7, 2017

financial statements

for the years ended March 31, 2017 and 2016

Statements of Financial Position As at March 31, 2017 and 2016

	Notes	2017 \$	2016 \$
Assets			
Current assets			
Cash – held in trust by University of British Columbia		617,428	832,537
Cash – held at bank		399,987	446,354
Accounts receivable		-	74,833
Contributions receivable		-	4,000
Unspent research and knowledge mobilization grants paid			
to participating institutions	5	2,650,223	1,792,680
Prepaid expenses		19,789	43,970
		3,687,427	3,194,374
Non-current assets			
Capital assets	6	4,438	5,721
		3,691,865	3,200,095
Liabilities			
Current liabilities			
Accounts payable and accrued liabilities		117,896	160,360
Deferred contributions	7	3,488,418	2,879,148
Deferred capital asset contributions	7	4,438	5,721
		3,610,752	3,045,229
Net assets		81,113	154,866
		3,691,865	3,200,095

The accompanying notes are an integral part of these financial statements.

APPROVED BY THE BOARD OF DIRECTORS

Slando.

Sheila Laredo, Chair, Board of Director

David Ure, Chair, Finance and Audit

financial statements

for the years ended March 31, 2017 and 2016

Statements of Operations and Changes in Net Assets

For the years ended March 31, 2017 and 2016			
	Notes	2017	2016
		\$	\$
Receipts			
Contribution from Networks of Centres of Excellence	7	3,472,693	3,578,680
Contribution from Institute for Health System			
Transformation and Sustainability	7	677,842	219,828
Conference registration fees and other support		103,500	73,314
Amortization of deferred capital contributions	7	1,828	1,749
		4,255,863	3,873,571
Expenditures			
Communications		40,993	33,157
Amortization		1,828	1,749
Insurance		7,466	7,527
Professional and consulting fees		67,538	126,073
Research and knowledge mobilization grants	5	3,010,391	2,451,190
Research support and training		343,470	383,845
Salaries and benefits		592,874	555,852
Supplies and office costs		28,412	36,816
Travel, meetings and networking		236,644	270,520
		4,329,616	3,866,729
Excess (deficiency) of receipts over expenditures		(73,753)	6,842
Net assets, beginning of year		154,866	148,024
Net assets, end of year		81,113	154,866

The accompanying notes are an integral part of these financial statements.

financial statements

for the years ended March 31, 2017 and 2016

Statements of Cash Flows

For the years ended March 31, 2017 and 2016		
	2017	2016
	\$	\$
Cash flows from (used in) operating activities		
Excess (deficiency) of receipts over expenditures	(73,753)	6,842
Non-cash items		
Amortization	1,828	1,749
Changes in working capital items		
Accounts receivable	74,833	[32,415]
Contributions receivable	4,000	94,469
Unspent research and knowledge mobilization grants	(857,543)	(1,158,823)
Prepaid expenses	24,181	(13,571)
Accounts payable and accrued liabilities	(42,464)	[88,212]
Deferred contributions	607,987	1,299,743
	(260,931)	109,782

Purchase of furniture and equipment	(545)	[3,208]
Instance (destance) in cach	(261 476)	106 574
Cash, beginning of year	1,278,891	1,172,317
Cash, end of year	1,017,415	1,278,891
Cash composed of:		
Cash – held in trust by University of British Columbia	617,428	832,537
Cash – held at bank	399,987	446,354
	1,017,415	1,278,891

The accompanying notes are an integral part of these financial statements.

for the years ended March 31, 2017 and 2016

1. Nature of Operations

Kids Brain Health Network ("KBHN" or the "Network") is a not-for-profit organization established by the Government of Canada's Networks of Centres of Excellence ("NCE") Program. The NCE Program is a program of the Government of Canada administered jointly by the Natural Sciences and Engineering Research Council ("NSERC"), the Social Sciences and Humanities Research Council ("SSHRC") and the Canadian Institutes of Health Research ("CIHR") in partnership with Innovation, Science and Economic Development Canada and Health Canada.

The Network was established to promote research in disorders of brain development and the implementation of real life solutions to improve the lives of affected children and families. The Network pursues its mission through a variety of means, most prominently by distributing awards to its principal investigators through their participating institutions for approved research projects. Research projects must include a plan to mobilize the knowledge generated in a way that it will provide socio-economic benefit to Canada. This will typically be accomplished through partnerships with other organizations.

Kid's Brain Health Network Inc., formerly Neurodevelopment Network Inc., the manager of the Network, was formally incorporated under Part II of the Canada Corporations Act as a non-profit organization on December 9, 2009. Kids Brain Health Network Inc. changed its name from Neurodevelopment Network Inc. on August 5, 2016.

KBHN's receipts and expenditures are primarly composed of contributions received from the NCE program and disbursed on its behalf. KBHN may not be able to maintain its current level of operations should this funding be significantly reduced or ended.

2. Basis of Presentation

Statement of Compliance

These financial statements have been prepared in accordance with Canadian Accounting Standards for Not-for-Profit Organizations ("ASNPO") effective as of March 31, 2017.

Basis of Presentation

These financial statements have been prepared on the historical cost basis, except for certain financial instruments which are measured at fair value, as explained in the accounting policies set out in Note 3. These financial statements are presented using the deferral method of accounting for contributions.

3. Significant Accounting Policies

Accounting Estimates and Judgments

The preparation of these financial statements requires management to make estimates and judgments and to form assumptions that affect the reported amounts and other disclosures in these financial statements. The estimates and associated assumptions are based on historical experience and various other factors that are believed to be reasonable under the circumstances. The results of these assumptions form the basis of making the judgments about carrying values of assets and liabilities that are not readily apparent from other sources. Actual results may differ from these estimates under different assumptions and conditions.

for the years ended March 31, 2017 and 2016

3. Significant Accounting Policies continued

Accounting Estimates and Judgments continued

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognized in the period in which the estimate is revised if the revision affects only that period or in the period of the revision and further periods if the review affects both current and future periods.

Critical accounting estimates are estimates and assumptions made by management that may result in material adjustments to the carrying amount of assets and liabilities within the next financial year.

Critical accounting judgments are accounting policies that have been identified as being complex or involving subjective judgments or assessments. Critical accounting judgments used by the Network include the estimated useful life and future operating results from furniture and equipment, the recoverability of accounts receivable and contributions receivable, and the eligibility of expenditures for restricted contributions.

Cash

Cash contributions from the NCE are considered restricted and are to be held in trust and administered on KBHN's behalf by the University of British Columbia ("UBC"), the Network's host institution.

Financial Assets and Liabilities

Financial assets and financial liabilities are initially measured at fair value, adjusted by, in the case of a financial instrument that will not be measured subsequently at fair value, the amount of transaction costs directly attributable to the instrument. The Network subsequently measures its financial assets and financial liabilities at amortized cost. As at March 31, 2017, the recorded amounts of financial assets and financial liabilities approximate fair values.

Financial assets measured at amortized cost are tested for impairment when a significant adverse change has occurred during the period in the expected timing or amount of future cash flows. The amount of the write-down is recognized in net income and may be reversed in future periods if the assessment of impairment is revised.

Unspent Research and Knowledge Mobilization Grants Paid to Participating Institutions

Research and knowledge mobilization grants paid to participating institutions are deferred until the participating institution incurs eligible research costs, at which time they are recognized as research and knowledge mobilization grant expenditures.

Furniture and equipment

Furniture and equipment are recorded at cost and amortized on a declining balance basis over their respective estimated useful lives at annual rates of 20% (furniture) and 30% (computer equipment).

for the years ended March 31, 2017 and 2016

3. Significant Accounting Policies continued

Recognition of Receipts

The Network follows the deferral method of accounting for contributions, which include government grants. Funds are received from agencies of the Canadian federal government, the host institution, and other private and public sector partners. Contributions which have external restrictions governing the types of activities which they can be used to fund are deferred and recognized when the eligible expenditures are incurred. Contributions approved but not yet received at the end of the reporting period are accrued when collectability is reasonably assured.

Under the terms of the NCE agreement and Institute for Health System Transformation and Sustainability ("IHSTS") service contract, the funding received from the NCE and IHSTS will be directed to the granting of awards to the Network's participating institutions and the payment of operating and capital expenditures. When received, NCE and IHSTS contributions are deferred and recognized as revenue in the period in which the related expenditures are incurred by the Network or a participating institution.

Restricted contributions applied toward the purchase of furniture and equipment are deferred and recorded as receipts at the rate corresponding to the amortization rate of the related equipment. Unrestricted contributions, including conference registration fees and sponsorships, are recognized as receipts in the current period if the amount to be received can be reasonably estimated and collection is reasonably assured.

In-Kind Contributions

In-kind contributions from the host institution, which includes the provision of office space and technical and administrative support, and other organizations are not included in these financial statements.

Employee Future Benefits

KBHN's staff are eligible to join the UBC staff pension plan. KBHN's contribution for staff is approximately 9% of salary. In the event of funding deficiencies, KBHN's contributions remain fixed and benefits for members may be reduced. Accordingly, KBHN records contributions to this plan as expenditures in the year the contributions are made. Contributions to the plan made during the year amounted to \$34,800 (2016: \$26,500).

Income Taxes

KBHN is a not-for-profit entity and is not subject to Federal or Provincial income taxes.

for the years ended March 31, 2017 and 2016

4. Funding Agreements

Contribution from the NCE

In 2009, NSERC, SSHRC and CIHR agreed to contribute funding of \$19,572,000 to the Network over five years ending on December 23, 2015. This funding cycle was completed in the fiscal year ended March 31, 2015.

In December 2014, the same agencies agreed to contribute \$19,572,000 for a second cycle of funding from 2015 to 2020, as follows:

Fiscal Year	Total	
2014 - 2015	\$ 1,046,000	received
2015 - 2016	4,203,000	received
2016 - 2017	4,039,231	received
2017 - 2018	3,867,387	
2018 - 2019	3,278,382	
2019 - 2020	3,138,000	
Total Funding	\$ 19,572,000	_

The annual contributions will be released subject to the following conditions:

- Parliamentary appropriation of the funds in each fiscal period;
- Satisfactory progress, as determined by the NCE Secretariat, towards predetermined milestones for the NCE Network;
- Continuing eligibility of the NCE Network Host and the NCE Network; and
- Compliance with the terms of the funding agreement.

Contribution from the Host Institution

On January 22, 2010, KBHN entered into an agreement with UBC under which UBC will serve as the host institution for the Network, providing facilities and services for KBHN's administrative centre. A new agreement (the "Network Agreement") with UBC was entered into on February 1, 2016 for the second cycle of NCE funding.

The Network Agreement between KBHN and UBC provides a grant of \$200,000 over 5 years from 2016 to 2020 as well as in-kind support. In-kind support is not recorded in the financial statements and includes legal services, payroll, purchasing and grant management, management of intellectual property, information technology support and web hosting services.

Contribution from the IHSTS

On June 24, 2015, KBHN entered into a service contract with IHSTS under which KBHN was granted \$2,125,000 to support eligible neurodevelopment programs during a period of three years, from June 24, 2015 to March 31, 2019. During the year ended March 31, 2017, KBHN received \$681,119 (2016: \$840,000) of this grant from IHSTS.

for the years ended March 31, 2017 and 2016

5. Research and Knowledge Mobilization Grants and Expenditures

KBHN provides research and knowledge mobilizatoin grant funding for eligible research projects to the participating institution of the principal investigators of approved research projects. The grant funds are held in trust by the participating institution and are recorded as unspent research and knowledge mobilizatoin grants by KBHN until eligible research expenses are incurred by the principal investigators.

Unspent

	Unspent Balance, Mar 31, 2016 \$	Research Grants, Current Year \$	Research Expenditures, Current Year \$	Funds Returned, Current Year \$	Unspent Balance, Mar 31, 2017 \$
IHSTS grants					
Emily Carr University of Art + Design	6,285	82,125	(74,158)	-	14,252
Holland Bloorview	17,500	33,385	[33,477]	-	17,408
Queen's University	23,416	156,625	(97,986)	-	82,055
Simon Fraser University	32,750	99,287	[52,485]	-	79,552
Sunny Hill Health Centre for Children	-	13,178	[2,887]	-	10,291
University Health Network	47,500	65,000	[96,755]	-	15,745
University of British Columbia	65,842	257,548	(183,630)	-	139,760
University of the Fraser Valley	-	3,262	[1,084]	-	2,178
University of Victoria	[5,621]	939	[7,795]	-	[12,477]
	187,672	711,349	(550,257)	-	348,764
NCE grants					
Dalhousie University	324,456	205,723	[124,087]	-	406,092
Holland Bloorview	31,694	214,166	(184,619)	[2,602]	58,639
Hospital for Sick Children	45,197	210,273	(96,179)	-	159,291
Institut De Recherches Cliniques					
De Montreal (IRCM)	51,328	80,300	(104,932)	-	26,696
IWK Health Centre	101,252	187,441	[35,400]	-	253,293
King's University College	-	5,000	[3,639]	-	1,361
McGill University	138,446	298,887	[202,018]	-	235,315
McGill University Research Institute	116,891	107,475	(105,572)	-	118,794
McMaster University	160,715	190,290	[123,922]	[4,340]	222,743
Memorial University of Newfoundland	3,900	3,900	-	-	7,800
Mount Sinai Hospital	12,128	36,000	[48,128]	-	-
Queen's University	11,012	80,000	[75,878]	-	15,134
University Health Network	13,968	164,856	[190,223]	-	(11,399)
University of Alberta	63,003	228,099	[147,322]	(125)	143,655
University of British Columbia	211,025	538,382	[457,909]	-	291,498
University of Calgary	142,353	195,558	[112,648]	-	225,263
University of Manitoba	7,201	-	-	(7,201)	-
University of Ottawa	34,381	71,500	(105,290)	-	591
University of the Fraser Valley	8,091	-	[8,078]	-	13
University of Toronto	2	72,000	[72,002]	-	-
University of Victoria	20,757	-	[20,757]	-	-
York University	107,208	281,003	[241,531]	-	146,680
	1,605,008	3,170,853	(2,460,134)	(14,268)	2,301,459
Totals	1,792,680	3,882,202	(3,010,391)	(14,268)	2,650,223

notes to financial statements

for the years ended March 31, 2017 and 2016

6. Furniture and Equipment

Cost	\$
Balance at March 31, 2015	18,715
Additions	3,208
Balance at March 31, 2016	21,923
Additions	545
Balance at March 31, 2017	22,468
Accumulated Depreciation	
Balance, March 31, 2015	14,453
Amortization	1,749
Balance, March 31, 2016	16,202
Amortization	1.828

Balance at March 31, 2017	18,030
Carrying amount Balance, March 31, 2016	5,721
Balance, March 31, 2017	4,438

7. Deferred Contributions

Deferred Contributions

	Mar 31, 2017	Mar 31, 2016
NCE funda	\$	\$
NCE funds		4 5 7 7 0 6 4
Balance at the beginning of year	2,258,976	1,577,864
Grants from the NCE	4,039,231	4,203,000
Grants from the Host Institution	40,000	60,000
Amounts recognized as receipts during the year	(3,472,693)	[3,578,680]
Amounts applied toward furniture and equipment		
purchased during the year	(545)	[3,208]
	2,864,969	2,258,976
IHSTS funds		
Balance at the beginning of year	620,172	-
Grants from IHSTS	681,119	840,000
Amounts recognized as receipts during the year	(677,842)	[219,828]
	623,449	620,172
Other restricted funds		
Balance at the beginning of year	-	3,000
Grants received during the year	-	24,983
Amounts recognized as receipts during the year	-	[27,983]
	-	-
Balance at the end of year	3,488,418	2,879,148

notes to financial statements

for the years ended March 31, 2017 and 2016

7. Deferred Contributions continued

Deferred Capital Contributions Relating to Furniture and Equipment

	Mar 31, 2017 \$	Mar 31, 2016 \$
Balance at the beginning of year	5,721	4,262
Allocation of deferred contributions	545	3,208
Amounts amortized to revenue	(1,828)	[1,749]
Balance at the end of year	4,438	5,721

8. Kids Brain Health Foundation

Kids Brain Health Foundation ("KBHF") was incorporated in British Columbia under the Canada Not-for-profit Corporations Act on March 9, 2016. On July 14, 2016, KBHF was granted charitable registration by Canada Revenue Agency. The purpose of KBHF is to raise awareness of and funds for KBHN's research activities as well as the implementation of research discoveries.

As at March 31, 2017, KBHF has not received any contributions or donations. KBHN incurred professional fees and communication costs of \$15,834 (2016: \$20,343) related to the establishment and development of KBHF for the year ended March 31, 2017 which are included in the statement of operations and changes in net assets.

9. Risk Management

KBHN's activities expose it to financial risks which include credit risk and liquidity risk. The Network's risk management program focuses on the unpredictability of financial markets and seeks to maximize the Network's ability to meet its mandate.

Credit Risk

Credit risk is the risk of financial loss to KBHN if a counterparty to a financial instrument fails to meet its contractual obligations. The Network is exposed to credit risk from its cash and accounts receivable. The Network considers this risk to be minimal as cash as is on deposit at insured financial institutions and significant accounts receivable are due from major universities and government funding partners.

Liquidity Risk

Liquidity risk is the risk that the Network will not be able to meet its financial obligations as they come due. Accounts payable and accrued liabilities are due within the current operating period. KBHN's overall exposure to liquidity risk is minimal as the Network has sufficient assets to meet outstanding obligations.

for the years ended March 31, 2017 and 2016

10. Capital Management

KBHN defines its capital as the amounts included in net assets, deferred contributions and deferred capital contributions.

KBHN's capital management objectives are to meet its obligations under its funding agreements and to safeguard its ability to continue to pursue the objectives of the Network.

KBHN has certain external restrictions on the use of deferred contributions and deferred capital contributions, as set out in Notes 3 and 5. KBHN has internal control processes to ensure that the restrictions are met prior to utilization of these resources and has been in compliance with these restrictions throughout the period.

PROJECT TITLE:

CEREBRAL PALSY DISCOVERY PROGRAM (CPDP)

Principal Investigators:

Darcy Fehlings, MD, Professor in the Department of Paediatrics, University of Toronto, Senior Clinician Scientist Bloorview Childrens Hospital

Jerry Yager, MD, Professor, Department of Pediatrics, University of Alberta

PROJECT TITLE:

CHILDREN WITH NEURODEVELOPMENTAL DISABILITIES: MOVING TOWARDS HOLISTIC-COMPREHENSIVE APPROACHES IN DESIGNING AND EVALUATING NON-CATEGORICAL HABILITATION INTERVENTIONS

Principal Investigators:

Jean-Paul Collet, MD, PhD, Department of Paediatrics, University of British Columbia, Associate Head Research, Senior Researcher, BC Children's Hospital

William McKellin, PhD, Assistant Professor, Department of Anthropology, University of British Columbia

PROJECT TITLE:

FETAL ALCOHOL SPECTRUM DISORDER (FASD) RESEARCH PROGRAM: EARLY LIFE ADVERSITY, OUTCOMES, AND SECONDARY INTERVENTION AND PREVENTION

Principal Investigator:

James Reynolds, PhD, Professor, Department of Biomedical and Molecular Sciences, Queen's University

PROJECT TITLE:

DEVELOPMENT, IMPLEMENTATION, AND EVALUATION OF AN INTERNET-BASED BEHAVIOURAL SLEEP INTERVENTION FOR CHILDREN WITH NDD AND INSOMNIA (BETTER NIGHTS, BETTER DAYS FOR CHILDREN WITH NEURODEVELOPMENTAL DISABILITIES) SLEEP/WAKE APPLICATION (SWAPP) FOR CHILDREN WITH VARIOUS NEURODEVELOPMENTAL CONDITIONS

Principal Investigators:

Penny Corkum, PhD, Professor, Department of Psychology & Neuroscience at Dalhousie University

Shelly Weiss, MD, Professor, Department of Pediatrics, University of Toronto, Neurologist at the Hospital for Sick Children

Osman Ipsiroglu, MD, PhD, MBA, Professor, Department of Pediatrics, University of British Columbia

PROJECT TITLE:

FROM BIOSIGNATURES TO BEHAVIOURAL PROFILES IN AUTISM SPECTRUM DISORDERS

Principal Investigators:

Geoffrey Hall, PhD, Associate Professor, Department of Psychology, Neuroscience and Behaviour at McMaster University

Stephen Scherer, PhD, Director, the Centre for Applied Genomics at the Hospital for Sick Children, Professor, Department of Molecular Genetics, University of Toronto

PROJECT TITLE:

HEALTH ECONOMICS AND THE SOCIAL DETERMINANTS OF HEALTH AS A FRAMEWORK FOR UNDERSTANDING SOCIOECONOMIC AND QUALITY OF LIFE OUTCOMES AMONG CHILDREN WITH NEURODEVELOPMENTAL DISORDERS AND THEIR CAREGIVERS

Principal Investigators:

David Nicolas, PhD, Associate Professor, Faculty of Social Work, University of Calgary

Lucy Lach, PhD, Associate Professor, School of Social Work, Associate Member, Department of Pediatrics, Child Behaviour Development Program, McGill University

Jen Zwicker, PhD, Assistant Professor, School of Public Policy, University of Calgary

PROJECT TITLE:

NEUROETHICS EXCELLENCE AND SOCIETAL INNOVATION CORE (NESIC)

Principal Investigators:

Judy Illes, PhD, Professor of Neurology and Canada Research Chair in Neuroethics at the University of British Columbia

Éric Racine, PhD, Director and Professor, Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM)

PROJECT TITLE:

NEUROINFORMATICS CORE

Principal Investigator:

Paul Pavlidis, PhD, Professor, Department of Psychiatry and Centre for Brain Health

PROJECT TITLE:

KNOWLEDGE TRANSLATION: MAXIMIZING THE IMPACT OF RESEARCH AND TRAINING IN NEURODEVELOPMENTAL DISORDERS

Principal Investigator:

David Phipps, MBA, PhD, Executive Director, Research & Innovation Services, York University

PROJECT TITLE:

MINDFULNESS-BASED THERAPY FOR ADOLESCENTS WITH AUTISM SPECTRUM DISORDERS AND THEIR PARENTS

Principal Investigator:

Jonathan Weiss, PhD, Associate Professor, Department of Psychology, York University

PROJECT TITLE:

OPTIMIZING DEVELOPMENT AND OUTCOMES IN CHILDREN AND YOUTH WITH ASD

Principal Investigators:

Lonnie Zwaigenbaum, MD, Professor and Director, Autism Research, Division of Developmental Pediatrics, Faculty of Medicine and Dentistry University of Alberta

Stephen Scherer, PhD, Director, the Centre for Applied Genomics at the Hospital for Sick Children, Professor, Department of Molecular Genetics, University of Toronto

PROJECT TITLE:

TESTING NEURAL PRECURSORS AS MEDIATORS AND FACILITATORS OF CONSTRAINT INDUCED MOVEMENT THERAPY IN CEREBRAL PALSY

Principal Investigators:

Derek van der Kooy, PhD, Professor, Department of Medical Genetics and Microbiology, University of Toronto

Michael Fehlings, MD, PhD, Professor of Neurosurgery, University of Toronto, Head Spinal Program, Toronto Western Hospital

Alan Peterson, PhD, Professor, Department of Medicine, McGill University

Andras Nagy, MD, PhD, Professor, Department of Obstetrics & Gynecology, University of Toronto

Cindi Morshead, PhD, Professor and Chair, Division of Anatomy, University of Toronto

BC Projects

PROJECT TITLE:

SLEEP/WAKE APPLICATION (SWAPP) FOR CHILDREN WITH VARIOUS NEURODEVELOPMENTAL CONDITIONS

Principal Investigators:

Dr. Osman S. Ipsiroglu, MD, PhD, Clinical Associate Professor, Departments of Paediatrics and Psychiatry, Faculty of Medicine, University of British Columbia (UBC), Vancouver, BC

Dr. Chris Shaw, PhD, Associate Professor/Associate Director at the School of Interactive Arts and Technology (SIAT), Simon Fraser University Surrey, Surrey, BC

Ms. Caylee Raber, MDes, Director, Health Design Lab, Emily Carr University of Art and Design, Vancouver, BC

PROJECT TITLE:

TOTTECH: TANGIBLE, ORGANIZING AND THERAPEUTIC TECHNOLOGIES TO ENGAGE CHILDREN

Principal Investigator:

Machiel Van der Loos, Associate Professor, Department of Mechanical Engineering, University of British Columbia

PROJECT TITLE:

DINO ISLAND VIDEO GAME FOR AUTISM AND FASD

Principal Investigators:

Kimberly A. Kerns, PhD, R.Psych, Professor Emeritus, Psychology Department, University of Victoria

Sarah J. Macoun, PhD, R.Psych, Assistant Professor, Psychology Department, University of Victoria

Sylvain Moreno, PhD, School of Engineering, Simon Fraser University

Woonam Kim, Assistant Professor, Faculty of Design and Dynamic Media, Emily Carr University of Art and Design

PROJECT TITLE:

NOVEL ASSESSMENT TOOL FOR FASD BASED ON EYE MOVEMENT BEHAVIOURS

Principal Investigators:

James Reynolds, PhD, Professor, Centre for Neuroscience Studies, Queen's University

Tim Oberlander, MD, Department of Pediatrics, University of British Columbia

Christine Loock, MD, Department of Pediatrics, University of British Columbia

PROJECT TITLE:

NEURO-EXERGAMING FOR ALL: BRINGING FUN, SOCIAL ENGAGEMENT AND PHYSICAL ACTIVITY TO CHILDREN WITH CP AND CHILDREN WITH FASD

Principal Investigators:

Nicholas Graham, Queen's University

Darcy Fehlings, Holland Bloorview Kids Rehabilitation Hospital

James Reynolds, Queen's University

PROJECT TITLE:

PHYSICAL ACTIVITY PROGRAM (PAP) EFFECTS ON CHILDREN AND YOUTH WITH NEURODEVELOPMENTAL DISABILITIES

Principal Investigators:

Dr. Jean-Paul Collet, MD, PhD, Professor, Pediatrics Department, University of British Columbia

Dr. William McKellin, PhD, Professor, Anthropology Department, University of British Columbia

Dr. Anton Miller, MB. ChB., FRCPC. Clinical Associate Professor, Pediatrics Department, University of British Columbia.

Dr. Jonathan Weiss, PhD, Associate Professor, Psychology Department, York University

Dr. Annette Majnemer, PhD, FCAHS, Professor, School of Physical & Occupational Therapy, McGill University

Dr. Louise Mâsse, PhD, Associate Professor, Pediatrics Department, University of British Columbia

Dr. Rollin Brant, PhD, Professor, Department of Statistics, University of British Columbia

Dr. Grace larocci, PhD, Professor, Psychology Department, Simon Fraser University

PROJECT TITLE:

AT HOME WIRELESS EEG SEIZURE MONITORING FOR FASD DIAGNOSIS

Principal Investigators:

Peter L. Carlen, MD, FRCPC, University Health Network, University of Toronto

James N. Reynolds, PhD, Department of Biomedical and Molecular Sciences, Queen's University

Tim Oberlander, MD, FRCPC, Child and Family Research Institute

Christine Loock, MD, FRCPC, Sunny Hill Health Centre for Children

Network Investigators (131)

Lynne Abele-Webster Evdokia Anagnostou John Andersen Pantelis Andreou Gail Andrew Rubab Arim Erin Barker **Christian Beaulieu** Sue Becker Teresa Bennett Joseph Beyene **Rachel Birnbaum** Alec Black Patricia Boechler Susan Bogels **Rollin Brant** Jessica Brian Cary Brown Susan Bryson David Buckley Peter Burton Peter Carlen Albert Chudley Jean-Paul Collet **Evelyn Constantin** Jocelynn Cook Penny Corkum Ying Cui Esther de Bruin Irene Drmic Eric Duku Salhab el Helou Mayada Elsabbagh

Herbert Emery Carl Ernst Alan Evans Nora Fayed **Darcy Fehlings Michael Fehlings** Christoph Fusch Victoria Galea **Stelios Georgiades** Roger Godbout Helly Goez **Daniel Goldowitz** Jan Gorter **IP** Gouin Mijna Hadders-Algra **Geoffrey Hall** Ana Hanlon-Dearman Antony Hodason Gabriella Horvath Grace larocci Judy Illes Osman Ipsiroglu Kathy Keiver **Kimberly Kerns** Adam Kirton Dafna Kohen Chaya Kulkarni Azadeh Kushki Lucyna Lach **Catherine Lebel** Nicole Letourneau Louise Mâsse Sarah Macoun

Annette Majnemer Patrick McGrath William McKellin Steven Miller Anton Miller Pat Mirenda Sarah Moore Cindi Morshead Christopher Mushquash Andras Nagy **David Nicholas** Tim Oberlander Heather O'Brien Maryam Oskoui Paul Pavlidis Jacqueline Pei Alan Peterson **David Phipps** Shelley Phipps Alison Pritchard Orr Éric Racine Carmen Rasmussen Graham Reid Jim Reilly James Reynolds Wendy Roberts Gabriel Ronen Colin Ross David Rothwell Joanne Rovet Amy Salmon Stephen Scherer Sarah Shea

Network Investigators (131) continued

Michael Shevell Keiko Shikako-Thomas Wayne Simpson Graham Sinclair Isabel Smith Ranil Sonnadara **Elizabeth Sowell** Sylvia Stockler Peter Szatmari Suzanne Tough Wendy Ungar **Tracy Vaillancourt** Michiel van de Panne Derek van der Kooy Machiel Van der Loos Clara van Karnebeek Esias van Rensburg Naznin Virji-Babul Joanne Volden Charlotte Waddell Wyeth Wasserman Joanne Weinberg **David Whitehurst Jonathan Weiss** Shelly Weiss Rosanna Weksberg Ron Wevers Ellen Wood Jerome Yager Lonnie Zwaigenbaum Jennifer Zwicker **Jill Zwicker**

Network Trainees (217)

Kelsey Adams Tony Ahn Nicole Ali Carly Albaum Babak Alipanahi Basma Al-Jabri Abdullah Alshememry John Aspler Icoquih Badalli Hooman Bagheri Samantha Baglot Ashley Bahry Sacha Bailey Kayla Baker Soela Bandaly Vanessa Bao Paolo Bazzigaluppi Stephanie Beldick **Renee Bernard** Mai Berger Nadia Beyzaei Nathalie Binnion Karen Black Katelynn Boerner Aline Bogossian Daphne Bollen Tatiana Bregman Leah Brown Zsuzsa Buckwald-Lindenmaier Priscilla Burnham Riosa Roxanne Caron Hillary Carpenter

Ariel Cascio Michelle Chakraborti Brie Chauncey Lawrence Chen Marjolaine Chiccoine Isabelle Chouinard Phil Chrapka Patrick Ciechanski Andrea Constantinof Jenna Crawford Dutton Dan Fiona Davidson Erik de Jong Kiret Dhindsa Nina Di Pietro Trish Domi Laura Donovan Sarah Dorsey Colby Draney Britt Drogemoller Ellen Drumm Stephanie Duncan Lisa Dzadzamia Derek Eng Mariam Faiz Stephanie Fehertoi Katherine Flannigan Gila Foomani Ellis Freedman lan Garber **Emily Gardiner** Genevieve Gariepy

Network Trainees (217)

Heather Gautreau Aisha Ghani Kamaldeep Gill Mojgan Gitimoghaddam Gina Glidden Jeff Grab Raquel Graham **Rachel Grant** Madeleine Green-Holland Jessie Guo Aris Hadjinicolaou **Carolin Hahnel Drew Halliday** Eva Haspels Jordana Hildebrant Ellie Hogan Parker Holman Sharmin Hossain Sarah House Melissa Howlett Sarah Hutchison Candice Ip lason Issacs Sara Izadi Daniel Jay Melanie Jeffrey Anastaija Jemcov William Jones Aamena Kapasi Precilia Kong Kayla Kozma

Thanos Kritharis Brian Krug Alexandra Kruse Andrea Kuczynski Jessica Lee Yi Jui (Alex) Lee Jonathan Leef Thomas Lehoux Brenna Li Justin Licari Nathaniel Lim Graham Little James Liu Xiangyu Long Krista Longeway Hayami Lou Lei Lu Alexandre Lussier Ogan Macarci Jennifer MacSween Neemat Mahmud Ogan Mancarci Jonathan Marr Sabah Master Allison Matthews-Cotton Danielle Mattson Andrea Maughan Graham McAllister **Daniele Merico** Rebecca Merkley Taylor Mutis

Regula Neuenschwander Adam Newton Pamela Ng Antoinette Nguyen Bryce Odell Sezgi Ozel Larissa Padua Angelina Paolozza Carmela Paolozza Soh Yun Park Andre Pepin Jennifer Poole Jelena Popic Kathryn Post Ann-Marie Przyslupski Akshay Puli Sarah Pyne Pei Qin Sanja Radulovic Lisa Anne Rasmussen Sarah Raza Amber Rieder Gabrielle Rigney Rebecca Ruddy Prakasham Rumajogee Frank Russell Nadia Sachewsky Lori-Ann Sacrey Sandra Salem Gurtej Sangha Giulia Santin

Network Trainees (217)

Sarah Sarabadani Tal Savion-Lemieux Derek Schaper Veronica Schiariti **Rilla Schneider** Ryan Sefid Gabrielle Semail Valbona Semovski Mariane Senetac Marcel Severe Aidan Shair John Sheehan Meaghan Shevall Navid Shirzad Leia Shum Rachel Sllberg Michelle Siu Anne-Sophie Smilga Tamara Speth Kaylee Sohng **Christinal Sooklal Rianne Spaans** Dunn Stephanie Samantha Sterling Peter Sterling Sonya Strohm Ricky SuiKamila Szulc Dan Szymczak Jennifer Talbot Kim Tan-MacNeill **Dmitry Tebaykin**

Abe Teklemariam Rackeb Tesfaye Marie-Pierre Tessier Shelby Thompson Victoria Ting Lilah Toker Elaine Toombs **Michelle Tougas** Shreejoy Tripathy Kerrie Tsigounis Daisuke Umebayashi **Bulmaro Valdés** Kathy Unsworth Balazs Varga Reaz Vawda Ilan Vonderwalde Natalie Wagner Alexandra Wagner Jessica Walesch Brad Watson Cindy Xiao Yicheng Xie Samantha Yammine Mandy Yee Paul Yejong Yoo Jenny Yoon Amber Young Connie Yuen Rosslynn Zulla

Network Senior Research Staff (19)

Paul Bradshaw Helen Carlson Lara El-Khatib Susan Kobus Ni Lan Sydney Dale-McGrath Dayle McCauley Anneliese Poetz Charlis Raineki Lysanne Rivard **Christine Rogers** Sanja Rogic Lauren Switzer Maja Tarailo-Graovac Sarah Treit Carol Wilson Ephrem Zewdie Linhua Zhang Dongming Zhou

Network Highly Qualified Personnel (HQP) (50)

Svetlana Altamentova Edward Armstrong Kate Bernardi Mike Chalupka Stephanie Chow Brenda Coles-Takabe Lorna Colli Olivia Conlon **Russel** Cooper **Nicole Cousins** Danielle Dalziel Erin Dowds Paula Dunn Sasha Dvck Annahita Ehsan Linda Ellis Kirsten Graham Iordana Hildebrandt Kevin Griffin Michal Krawcyzk Ramesh Lamsal Lisa-Marie Langaigne Nina Lantinga Justin Leong Anya Lundy

Alexander MacIntosh Stacey MacWilliam Neemat Mahmud Michael-Anne Markham Terry McCormick Dianne McGrath Marv McNeil Shanthini Mylvaganam Irene O'Connor Kathleen O'Grady Adeena Persaud Meera Ramani Iana Roberto Ellen Robertson Stacie Ross Susan Scott Michelle Shalinsky Sonya Strohm Venki Subramaniam Larry Tuff Amber Vance Sophie Wang Diane Wickenheiser Wayne Yu Natalie Zizzo

Founding Investigators

Ronald Barr Bruce Bjornson Tom Boyce Lara Boyd lessica Brian Jim Frederick Brien Richard E. Brown Max Cynader Marc Del Bigio David Eisenstat Ian Friedman Deborah Giaschi Ruth Eckstein Grunau **Richard Hawkes** Michael Hayden Anthony Herdman Clyde Hertzman William Honer Sheila Innis K.S. Joseph Michael Kobor Bryan Kolb **Evelyn Lambe** Suzanne Lewis Catherine Limperopoulos Bruce McNaughton Michael Meaney Ravi Menon Freda Miller Tim F. Oberlander Timothy O'Connor Catharine Helen Rankin Urs Ribary Bryan S. Richardson Stuart Shanker Isabel M. Smith Moshe Szyf Derek van der Kooy Wyeth W. Wasserman Daniel Weeks Janet Werker lan Q. Whishaw

Corporate Information

Administration

Daniel Goldowitz, *Scientific Director* James Reynolds, *Deputy Scientific Director* Tom Philpott, *Executive Director*

Board of Directors

Sheila Laredo, *Chair* Colin Deacon, *Vice Chair* Margaret Clarke Patrick Lafferty Glenys Godlovitch Dan Goldowitz J.P. Heale Peter Morand David Phipps Carol Richards Vasanthi Srinivasan Donna Thomson Kathleen Thurber David Ure

Scientific Advisory Committee

Samuel Weiss, *Chair* Bernie Devlin Joseph Fins Jay Giedd Neal Halfon Mark Hoffman Ivica Kostovic Pat Levitt Edward Riley

Research Management Committee

Richard Hawkes, *Chair* Julia Alleyne Mark Bieda Chris Fibiger Jan Friedman Daniel Goldowitz Mary Johnston Bryan Kolb Lucy Osborne James Reynolds Vivien Symington Laura Williams

Research Training Committee

Lucy Osborne, *Chair* Christian Beaulieu Richard Brown David Eisenstat Kathryn Murphy Bryan Richardson Jill Zwicker

Corporate Information

Staff

Bethany Becker, Communications Manager Tana David, Administration & Governance Coordinator Erica Lamb, Communications Assistant Kirsten Lawrie, Senior Administrator Su Han Ong, Training Assistant Tom Philpott, Executive Director Anthony Santelices, Project Coordinator Anita Sham, Administrative Assistant Shum Sidhu, Finance Manager Alice Sze, Finance Manager Doug Swanson, Research and Training Manager Jovana Vranic, Communications Assistant Pierre Zwiegers, Interim Administrative Assistant

Auditors

Hay & Watson, Chartered Accountants

Legal Counsel

Borden Ladner Gervais LLP, Vancouver BC

network community partners

Network Members

- 1. Dalhousie University
- 2. Holland Bloorview Kids Rehabilitation Hospital
- 3. Institut de recherches cliniques de Montréal (IRCM)
- Izaak Walton Killam (IWK) Health Centre Foundation (Halifax)
- 5. King's University College at Western
- 6. McMaster University
- 7. Memorial University of Newfoundland
- 8. Mount Sinai Hospital
- 9. Queen's University
- 10. The Hospital for Sick Children
- 11. The Governing Council of the University of Toronto
- 12. The Governors of the University of Alberta
- 13. The Governors of the University of Calgary
- 14. The Research Institute of the McGill University Health Centre
- 15. The Royal Institution for the Advancement of Learning / McGill University
- 16. The University of Western Ontario
- 17. Université Laval
- 18. University Health Network (Ontario)
- 19. University of British Columbia
- 20. University of Ottawa
- 21. York University

Industry Partners and Supporters

- 1. Athena Diagnostics
- 2. Avertus Epilepsy Technologies
- 3. Cell Cure Neuroscience Ltd
- 4. Club Aviva
- 5. Conquer Mobile
- 6. Dymaxia
- 7. Guarana Technologies
- 8. PARTEQ
- 9. REDCap (Research Electronic Data Capture) Software
- 10. SR Research
- 11. Shailah Interactive
- 12. Advanced Orthomolecular Research
- 13. Agri-Food Discovery Place

Other Affiliated Universities and Research Institutes

- Centre for Molecular Medicine and Therapeutics [CMMT]
- 2. Dalhousie University Industry Liaison and Innovation
- 3. Douglas College
- 4. Genome Canada
- 5. Humber College
- 6. Karolinska Institutet
- 7. Kennedy Krieger Institute, Johns Hopkins School of Medicine
- 8. Lakehead University
- 9. Mount Sinai Hospital (New York)
- 10. Neuroscience and Mental Health Institute, University of Alberta
- 11. Ontario Institute for Regenerative Medicine
- 12. PopDataBC
- 13. Simon Fraser University
- 14. Sunny Hill Health Centre for Children
- 15. Telethon Kids Institute (Australia)
- 16. Thompson Rivers University
- 17. Toronto Western Hospital, Krembil Research Institute
- 18. University of Manitoba
- 19. University of Sydney
- 20. University of Victoria
- 21. University of Western Ontario
- 22. University of the Fraser Valley
- 23. Wayne State University
- 24. Women's and Children's Health Research Institute

network community partners

Federal Departments and Agencies

- 1. Canadian Institutes of Health Research
- 2. Institute of Human Development, Child and Youth Health (IHDCYH)
- 3. NSERC/CIHR CHRP
- 4. Ministry of Sports and Disabilities
- 5. Statistics Canada
- 6. Public Health Agency of Canada
- 7. Health Canada
- 8. Brain Canada
- 9. Federal Government of Canada
- 10. Office for Disability Issues

Provincial and Municipal Departments and Agencies

- 1. Alberta Children's Hospital Research Institute
- 2. BC Ministry of Children and Family Development
- 3. BC Ministry of Education
- 4. BC Ministry of Health
- 5. BC Ministry of Social Development and Social Innovation
- 6. BC Women's Hospital & Health Centre
- 7. Centre for Commercialization of Regenerative Medicine
- Centre intégré universitaire de santé et de services sociaux du Centre-Ouest-de-l'Île-de-Montréal – Centre de réadaptation MAB-Mackay
- 9. Office des Personnes Handicappés du Québec
- 10. Ontario Brain Institute
- 11. Ontario Ministry of Child and Youth Services
- 12. Régie de l'assurance maladie du Québec
- 13. Central Elementary School
- 14. Chilliwack School District SD33, British Columbia
- 15. City of Toronto Children's Services
- 16. Gulf Islands School District SD64, British Columbia
- 17. Sooke School District SD62, British Columbia
- 18. Sullivan Heights Secondary, Surrey BC
- 19. RAM-Q Quebec
- 20. Vancouver Technical Secondary

Non-Profit Organizations

- 1. Abilities Center (Whitby, ON)
- 2. AGE-WELL Inc. NCE
- 3. Allen Institute for Brain Science
- 4. Alva Foundation
- 5. Autism Awareness Center Inc.
- 6. Autism Canada
- 7. Autism Nova Scotia
- 8. Autism Ontario
- 9. Autism Community Training society (ACT)
- 10. Autism Speaks Canada
- 11. Baby Siblings Research Consortium
- 12. BC Pediatric Society
- 13. Canada FASD Research Network
- 14. Canadian ADHD Resource Alliance (CADDRA)
- 15. Canadian Association of Pediatric Health Centres (CAPHC)
- 16. Canadian National Perinatal Research Meeting
- 17. Canadian Neonatal Brain Platform
- 18. Canadian Sleep Society (CSS)
- 19. CanFASD
- 20. Canuck Autism Network
- 21. Catholic Social Services
- 22. Centre de réadaptation Marie Enfant
- 23. Centre for ADHD Awareness Canada (CADDAC)
- 24. Centre for Commercialization of Regenerative Medicine
- 25. Centre for Interdisciplinary Research in Rehabilitation (CRIR)
- Centre intégré universitaire de santé et de services sociaux du Centre-Ouest-de-l'Île-de-Montréal – Centre de réadaptation MAB-Mackay

network community partners

- 27. Cerebral Palsy Association in Alberta
- 28. Cerebral Palsy Association of BC
- 29. Cerebral Palsy Association of Manitoba
- 30. Cerebral Palsy Association of Saskatoon
- 31. Cerebral Palsy Foundation of New Brunswick
- 32. CHILD-BRIGHT SPOR
- 33. Child Health BC
- 34. Children's Aid Society Toronto
- 35. Children's Hospital of Eastern Ontario
- 36. Children's Hospital of Philadelphia
- 37. Citizen Advocacy Ottawa
- 38. Club Aviva
- 39. CP Canada Network
- 40. Dilico Anishinabek Family Care
- 41. Down Syndrome Research Foundation
- 42. Edith Strauss Foundation
- 43. FASD Counselling and Consultation
- 44. FASD Diagnostic
- 45. FASD London Regions Assessment Clinic
- 46. FASD Waterloo Region
- 47. Firefly/Northwestern Ontario FASD Diagnostic clinic
- 48. Geneva Centre for Autism
- 49. Glenrose Rehabilitation Hospital Foundation
- 50. Grandview Children's Centre
- 51. Hamilton Health Sciences
- 52. Home of Hope
- 53. Humber Child Care Centre
- 54. Interior Health Authority
- 55. International Neuroinformatics Coordinating Facility [INCF]
- 56. Janus Academy

- 57. Krembil Foundation
- 58. Lawson Foundation
- 59. Manitoba FASD Centre
- 60. Micha Books
- 61. Miriam Foundation
- 62. MITACS
- 63. Montreal Children's Hospital Foundation
- 64. National CP Registry; McGill University
- 65. OHEYS Autism Programs
- 66. Ontario Federation for Cerebral Palsy
- 67. ParticipACTION
- 68. ResearchImpact
- 69. RICHER Initiative, BC Children's Hospital
- 70. Richmond Therapeutic Riding
- 71. Rick Hansen Foundation
- 72. Shailah Interactive
- 73. Sick Kids Infant Mental Health Promotion
- 74. Simons Foundation Autism Research Initiative
- 75. Sinneave Foundation Ability Hub
- 76. Soccer Dogs
- 77. Southlands Therapeutics
- 78. Special Olympics at the National and BC Level
- 79. Strongest Families Institute
- 80. Summit School
- 81. Sunny Hill Health Centre for Children
- 82. Thames Valley Children's Centre
- 83. THREE TO BE Foundation
- 84. Toronto General and Western Hospital Foundation
- 85. Trevor Williams Kids Foundation
- 86. Wellness Resiliency and Partnership Project
- 87. YMCA Quebec and Atlantic

contributors

Photography

Cover image:

Holland Bloorview Kids Rehabilitation Hospital Communications & Public Affairs

Access to Early Diagnosis and Services:

P. 10: Dr. Lorey Sacrey

Supporting Social Skills and Self Regulation:

P. 11 and 12: Stacie Turner *On the Spectrum* P. 13: Holland Bloorview Communications and Public Affairs P. 14: Shannon Lepere for Dilico Anishinabek Family Care

P. 15: Club Aviva

Schools and Children with Neurodisabilities:

P. 17: Joyce Hamelin P. 18: Bethany Becker

P. 19: Shmoofypoof Creative courtesy of Caleb Goeneweg

Transitions:

P. 21 and P. 23: Stacie Turner On the Spectrum P. 24 and P. 25: TEDx YorkU Salon, Spectrum https://www.youtube.com/watch?v=vm0INPrA0yY

Equity and Access across Disorders and Geography:

P. 29: winnipeg.ctvnews.ca P. 31 and P. 32: Civil Societies of Canada delegation to the Convention on the Rights of Persons with Disabilities

Contributors

Bethany Becker, Communications Manager Vanessa Hrvatin, Staff Writer Erica Lamb, Communications Assistant Elizabeth Samuels, Policy Intern Jovana Vranic, Communications Assistant

Design

tim gottschick / www.bay6creative.com

Kids Brain Health Network

The University of British Columbia Child and Family Research Institute 950 W. 28th Avenue Vancouver, BC V5Z 4H4

www.kidsbrainhealth.ca

604.875.2424 ext 5436







A CANADIAN NETWORK OF CENTRES OF EXCELLENCE