



# Centres for Leadership

## 2017-18 Centres for Leadership (CfL) funded initiatives

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### Cross Centres initiatives

#### 1. Development of a remote monitoring system for heart rate and oxygen levels to be used by parents of children with disabilities (CfL in Participation and Inclusion (P&I) and Innovation)

**Year: 1**

**Contributors:** Pierre Duez (Engineer, BRI), Andrea Hoffman (Physician, Clinical Team Investigator (CTI)), Sadia Qureshi (Family Leader), Chitra Gnanasabesan (Respiratory Therapist Coordinator), Maryanne Fellin (Clinical Resource Nurse).

**Programs/organizations:** PRISM lab Bloorview Research Institute, Complex Continuing Care inpatient unit.

**Client and family need:** For some children with medical complexity continuous monitoring is an essential part of their care but this often requires that parents/caregivers remain at their child's side in order to observe the monitor. This impacts both child and family independence and quality of life.

**Vision and impact statement:** It is this need for close monitoring that inspired a father/engineer to develop an innovative device that connects to the digital output from his daughter's heart rate and oxygen saturation monitoring device and sends the information directly to his smart phone and smart watch. The ultimate goal of this work is to make this technology widely available to parents and caregiver and improve client and caregiver quality of life.

**Deliverables:** Remote monitoring prototype with infrastructure, data and privacy review report.

**Funding:** \$20,000

## 2. Putting weighty topics into action: Sharing stories “from the floor” through a knowledge translation casebook to foster positive weight-related conversations (CfL in Child Development (CDP) and Innovation)

**Year: 1**

**Contributors:** Amy McPherson (Scientist), Christine Provvidenza (Knowledge Translation Specialist (KTS)), Susan Cosgrove (Family Leader), Julia Lyons (Registered Nurse (RN), CTI), Shannon Crossman (Artist), Jill Hamilton (Endocrinologist, The Hospital for Sick Children.), Alissa Steinberg (Dietitian, The Hospital for Sick Children.), Katie Mah (PhD student), Evdokia Anagnostou (Senior Clinician Scientist).

**Programs/organizations:** ProFILE Lab and Autism Research Centre Bloorview Research Institute, Child Development, Participation and Inclusion, Evidence to Care and the Hospital for Sick Children.

**Client and family need:** Children with disabilities have two to three times higher obesity rates than non-disabled children but weight management is infrequently addressed in encounters with healthcare professionals who feel under-skilled to talk about this topic.

**Vision and impact statement:** The aim of the project is to co-develop, with clients, families and clinicians, a digital casebook to support building skills to foster weight-related conversations.

**Deliverables:** Digital and hardcopy casebook.

**Funding:** \$15,000

## 3. KneuroKnits: Evaluating the impact of a knitting group for youth with neurodevelopmental disorders (e.g. autism) on social skills and anxiety (CfL in Innovation, CDP and P&I)

**Year: 1**

**Contributors:** Melanie Penner (Clinician Scientist), Azadeh Kushki (Scientist), Laura Hartman (Post Doc, Occupational Therapist), Patti Waters (PassionKnit), Katelin Cook (PassionKnit), Justine Wiegelmann (Behaviour Consultant, Geneva Centre for Autism), Rachel Cohen (Family Leader).

**Programs/organizations:** Child Development, Autism Research Centre Bloorview Research Institute, PassionKnit, Geneva Centre for Autism.

**Client and family need:** The majority of Canadian parents of children/youth with ASD have expressed a clear need for access to social skills groups or services and activity-based programs.

**Vision and impact statement:** KneuroKnits will build real world creative skills that will facilitate and evaluate impact of a knitting group on social interaction and anxiety of youth with neurodevelopmental disorders.

**Deliverables:** KneuroKnits pilot study, training and program materials.

**Funding:** \$17,000

## 4. Knowledge Translation Facilitator Network (KTFN): An Evidence to Care and Centres for Leadership partnership (funded by all four CFLs)

**Year: 2**

**Contributors:** Christine Provvidenza (Knowledge Translation Specialist), Ashleigh Townley (Knowledge Broker), Joanne Wincentak (Knowledge Broker), Shauna Kingsnorth (Evidence to Care Lead, Clinical Study Investigator (CSI)), Sean Peacocke (Manager, CFL).

**Programs/organizations:** Centres for Leadership, Evidence to Care.

**Client and family need:** At Holland Bloorview there is an opportunity to build development in knowledge translation (KT) competencies to foster integrated work and produce quality implementation and evaluation plans to better impact the lives of clients and families at Holland Bloorview.

**Vision and impact statement:** In year two, we aim to improve the KTFN curriculum, train eight new KT facilitators (including a family leader and student) and begin to drive our own dissemination activities.

**Deliverables:** Updated curriculum, eight new trained facilitators and journal article submission.

**Funding:** \$5,000

## Acquired Brain Injury Centre for Leadership

## 5. Transcranial Direct Current Stimulation (tDCS) for the treatment of concussion symptoms

**Year: 1**

**Contributors:** Deryk Beal (Clinician Scientist), Keelia Quinn de Launay (Student), Nick Reed (Clinician Scientist), Lily Riggs (Psychologist, CTI), Katia Simic (Speech Language Pathologist (SLP)), Nancy Kraetschmer (Family Leader), Ryan Hung (Physician, CTI), Leslie Ordal (Research Coordinator).

**Programs/organizations:** CONNECT Lab Bloorview Research Institute, Brain Injury Rehab Team, Concussion Research Lab.

**Client and family need:** With over 600 per 100,000 children and youth experiencing concussions annually there is a need to generate evidence on new treatments to improve recovery.

**Vision and impact statement:** The primary objective is to assess the therapeutic potential of transcranial direct current stimulation (tDCS), a form of non-invasive brain stimulation, in the context of childhood mild traumatic brain injury by testing the effects of tDCS on cognitive learning and recovery in youth with persistent concussion symptoms.

**Deliverables:** Intervention study of tDCS, presentations internally and internationally, article submission

**Funding:** \$18,000

## 6. Supporting students by enhancing educator knowledge about acquired brain injury.

**Year: 1**

**Contributors:** Shannon Scratch (Clinician Scientist), Christine Providenza (Knowledge Translation Specialist), Sara Stevens (Clinical psychologist/CTI), Alicia Brown (Family Advisor), Anne Hunt (Manager Student Led Concussion Clinic), Linda Ward (Principal, Bloorview School), Sara Diederichs (Community Resource Teacher-Secondary, Bloorview School Authority), Sheila Bennett (Brock University), Dawn Good (Brock University) Ruth Wilcock (OBIA), Sarah Bognar (SLP), Lisa Kakonge (SLP).

**Programs/organizations:** Brain Injury Rehab Team, Evidence to Care, Concussion Clinic, Bloorview School, Brock University, Ontario Brain Injury Association.

**Client and family need:** There is an opportunity to improve school reintegration of children with ABI to address observed cognitive, physical, behavioural, and emotional difficulties.

**Vision and impact statement:** The goal is to develop an education curriculum based on children and teachers' current needs to increase the understanding of ABI in the classroom.

**Deliverables:** Guided needs assessment workshop.

**Funding:** \$20,000

## 7. Exploring hopes, experiences and outcomes linked with use of the Lokomat robotic gait trainer in early stage rehabilitation of children following acquired brain injury (ABI): A mixed methods study

**Year: 2**

**Contributors:** Ryan Hung, (Physician, CTI), Virginia Wright (Scientist), Jennifer Ryan (Physiotherapist (PT)), Barbara Gibson (Scientist), Laura Ritchie (Family Leader), Kelly Brewer (PT), Gail Kirkwood (PT), Viola Cheng (PT), Tracy Lee (PT), Tricia Martin (PT Assistant), Greg Stefler (PT Assistant), Janet Bernstein (OT), Janet Woodhouse (OT).

**Programs/organizations:** Brain Injury Rehab Team (BIRT), SPARK Lab Bloorview Research Institute.

**Client and family need:** Learning to walk again is a common priority goal after a pediatric acquired brain injury (ABI) and there has been strong interest in using the Lokomat (robotic assisted gait training), but to date there are no Lokomat studies in pediatric ABI.

**Vision and impact statement** This study will be the first-ever determination of feasibility and outcomes associated with a clinically practical physiotherapy and Lokomat protocol for children with ABI.

**Deliverables:** Lokomat intervention for 20 clients, practice manual for Lokomat use with children with ABI, conference, journal submission to Brain Injury.

**Funding:** \$20,000

## 8. Moving the Pediatric Family Needs Questionnaire (FNQ-P) into clinical practice

**Year: 4**

**Contributors:** Caron Gan (APN/Family Therapist, CTI); Virginia Wright (Scientist), Christine Provvienza (Knowledge Translation Specialist), Lies Ferriman (Family Leader), Shannon Scratch (Clinician Scientist), Elaine Widdgett (Rehab Director), Kathy Gravel (Social Worker), Alysha Ladha (Physician), Claire Prescott (Clinical Resource Leader), Sara Diederichs (Community Resource Teacher-Secondary, Bloorview School Authority).

**Programs/organizations:** Brain Injury Rehab Team, Evidence to Care and SPARK Lab Bloorview Research Institute.

**Client and family need:** The need for family support after a child's acquired brain injury (ABI) is well documented, but there is no systematic way to assess and address these needs.

**Vision and impact statement:** In year 4 the team will pilot the FNQ at Holland Bloorview and begin to mobilize knowledge sharing and uptake at a national and international level.

**Deliverables:** FNQ-P pilot implementation, FNQ-P questionnaire and manual on Flint Box, implementation roadmap, presentations locally and internationally, article submission to Brain Injury journal.

**Funding:** \$15,000

## Child Development Centre for Leadership

### 9. Enhancing care for young people with muscular dystrophy: Addressing the human elements of progressive illness

**Year: 1**

**Contributors:** Jenny Setchell (Post Doc, PT), Barbara Gibson (Scientist), Laura McAdam (Physician, CTI), Marla Munk (Family Leader), Nadia Serrao (RN), Kelsey Bell (TR).

**Programs/organizations:** CDARS Lab Bloorview Research Institute and Child Development Program.

**Client and family need:** There has been considerable research in biomedical aspects of care but scarce attention to 'human' aspects such as living a fulfilling life, psychosocial health, and dealing with disability stigma for children with muscular dystrophy and their families.

**Vision and impact statement:** The project aims to implement previously co-created recommendations for human aspects of clinical care in the neuromuscular program at Holland Bloorview.

**Deliverables:** Implementation pilot, conference presentation, article submission to Developmental Medicine and Child Neurology.

**Funding:** \$20,000

## 10. Evaluating the benefits of providing information to families in advance of their health care visit

**Year: 1**

**Contributors:** Melanie Penner (Physician, Clinician Scientist), Brian Tsang (MD Candidate, UofT), Melissa Ngo (Family Support Specialist), Ruma Achrekar (Family Leader), Cheryl Peters (Family Leader), Martha Pilkington (Interim Senior Director and Operations Manager), Marilyn Ballantyne (Chief Nurse Executive, CSI), Janice Jaffar (Intake Coordinator), Louise Kublick (Manager).

**Programs/organizations:** Child Development Program, Bloorview Research Institute, Client and Family Integrated Care.

**Client and family need:** At Holland Bloorview, families can wait between 4 to 6 months to access some services which for parents and children can be emotionally challenging and can lead to missed appointments, reduced access to care, and longer wait times.

**Vision and impact statement:** The overarching aim of this project is to evaluate the effectiveness of the Outpatient Orientation program for supporting families while waiting for services.

**Deliverables:** Pilot study of the Outpatient Orientation program (estimated 200 families), presentations of results to Family Advisory Committee and the Canadian Pediatric Society.

**Funding:** \$10,000

## 11. Project LEApp (Learning to Eat App): Developing an iPad-based video modeling intervention for increasing food variety in children with autism spectrum disorder

**Year: 1**

**Contributors:** Sharon Smile (Physician, CTI), Cecilia Lee (Physician Fellow), Elaine Biddiss (Scientist), Rebecca Perlin (SLP), Christie Raffaele (OT), Moira Pena (OT), Annie Dupuis (Biostatistician, The Hospital for Sick Children.), Justine Wiegelmann (Behaviour Consultant, Geneva Centre for Autism), Adrienne Zarem (Family Leader), Christin Ferreira (Family Leader).

**Programs/organizations:** Child Development Program, PEARL Lab Bloorview Research Institute, Hospital for Sick Children, Geneva Centre for Autism.

**Client and family need:** Feeding difficulties are identified in up to 89% of children with autism and food selectivity is arguably the most difficult to manage and resistant to treatment which can have a significant impact on mealtime behaviours, parent-child interactions and nutrient intake and potential long-term consequences can include obesity and cardiovascular disease.

**Vision and impact statement:** Our objective is to develop an animated video modelling intervention (VMI) built from evidence based practices to target feeding selectivity in preschoolers with autism.

**Deliverables:** Clinical VMI prototype, presentation at The Hospital for Sick Children Research Day and Canadian Pediatric Society.

**Funding:** \$20,000



## 12. What are the mental health and wellness needs of young adults with spina bifida? A community based participatory research study

**Year: 1**

**Contributors:** Andrea Snider (Psychologist), Amy McPherson (Scientist), Sarah Keenan (Life Skills Coach, CTI), Dilshad Kassam-Lallani (Nurse Practitioner), Meghan McPhie (Psychology trainee), Shauna Beaudoin (Spina Bifida and Hydrocephalus Association of Ontario).

**Programs/organizations:** Child Development Program, Bloorview Research Institute, Participation and Inclusion, Anne Johnson Health Station and Spina Bifida and Hydrocephalus Association of Ontario (SBHAO).

**Client and family need:** With the significant increase of entry into adulthood for youth with spina bifida (SB) it has become imperative to understand how issues such as managing self-care, requirements of daily living, challenges with social engagement, employment, and the ability to live independently can have impact on the mental health and feelings of wellness for youth and adults with SB.

**Vision and impact statement:** To co-develop with clients, families, clinicians and researchers clinical guidelines for early identification and more effective intervention for mental health concerns.

**Deliverables:** Client and family survey and workshop, article in the SBHAO magazine.

**Funding:** \$10,000

## Innovation Centre for Leadership

## 13. Development of a lightweight high performance paediatric knee prosthesis for physically active children and youth with lower-limb amputations

**Year: 2**

**Contributors:** Jan Andrysek (Scientist), Sandra Ramdial (Prosthetist, Manager), Matthew Leineweber (Post Doc), Rafael Escamilla (Student), Brandon Burke (User), Amy Richardson (Prosthetist), Calvin Ngan (Legworks).

**Programs/organizations:** PROPEL Lab Bloorview Research Institute, Prosthetics and Orthotics, University of Toronto, Legworks.

**Client and family need:** Children with prosthetic legs are forced to compromise between prosthetic knees that allow good stance or good movement but not both, there is an opportunity to create a new prosthesis that can do both stance and movement and allow children to realize their full mobility and physical activity potential.

**Vision and impact statement:** The project team is combining the Paediatric AT-Knee with a newly designed swing-phase controller design to allow children the ability to achieve a strong stance and movement ability with their personal prosthesis.

**Deliverables:** Paediatric AT-Knee with swing controller prototype, article submission.

**Funding:** \$13,000

## 14. Improving the capacity of children to make informed decisions about their participation in research

**Year: 1**

**Contributors:** Steve Ryan (Senior Scientist), Sara Stevens (Clinical psychologist/CTI), James Anderson (Clinical Ethicist, SickKids), Anna Oh (Research Assistant), Meghan McPhie (Clinical Neuropsychology Intern), Paul Smith (Family Leader), Dolly Menna-Dack (Clinical Ethicist/REB Vice-Chair/Youth Facilitator), Barb Gibson (Senior Scientist), Marie Steele (Research Ethics Lead), Jennifer Ryan (Physiotherapist), Gloria Lee (Research Coordinator), Elizabeth Stephenson (REB Chair, SickKids).

**Programs/organizations:** Participation and Inclusion, Bloorview Research Institute.

**Client and family need:** Canadian policies governing research involving humans do not tell researchers what information to give and how to share it with children. Canadian regulations and policies require researchers to seek assent from children concerning participation in research, but there is little guidance concerning what information to give and how to share it with children. Children with disabilities are particularly vulnerable as they may have more trouble posing questions, seeking clarification and distinguishing research from typical care.

**Vision and impact statement:** The goal of this project is to seed a research program that can enhance and foster respect for children's developing autonomy by supporting real-world learning, and developing decisional capacity in children for translation into everyday clinical, educational, vocational, and social encounters.

**Deliverables:** Estimate the emerging validity of a new measure of what children understand about research studies, present findings at the Canadian Association of Research Ethics Boards Conference, and hold a workshop at Holland Bloorview to explore its potential application in clinical services.

**Funding:** \$18,000

## Participation and Inclusion Centre for Leadership

## 15. Evaluating the usability and effectiveness of a simulation package to teach service provider engagement strategies to promote the life skills of youth with disabilities

**Year: 2**

**Contributors:** Sarah Keenan (LSC, CTI), Gillian King (Scientist), Debra Cameron (UofT), Carolyn McDougall (OT), Andrea Definney (Therapeutic Recreation Specialist (TRS)), Michelle Peters (RA), Karly McCrone (Youth leader), Maureen Morris (Family Leader), Darlene Hubley (Teaching & Learning).

**Programs/organizations:** Participation and Inclusion, Bloorview Research Institute, Teaching and Learning, University of Toronto Occupational Therapy Department.

**Client and family need:** In practice expert therapists create opportunities that maximize client engagement and support successful clinical outcomes, we have an opportunity to train students and early career professionals in developing these types of engagement skills.



**Vision and impact statement:** Our objective in year 2 is to pilot and evaluate the effectiveness and usability of our educational package for teaching health professional students engagement strategies for youth with a disability in life skills programs.

**Deliverables:** Intervention pilot with a class of OT students.

**Funding:** \$9,000

## 16. Co-designing and implementing a health promotion program for adolescents with physical disabilities

**Year:** 3

**Contributors:** Kristen English (TRS), Amy McPherson (Scientist), Michelle Peters (Research Assistant), Vicki Keith (YMCA), Joanne Lee (Family Leader), Dolly Menna-Dack (Youth Advisor), Brenna Buchanan (P&I), Kelsey Bell (Life Skills Coach), Andrea DeFinney (TRS), Rachel McBurney (TRS), Sandy Steplock (Family Leader).

**Programs/organizations:** Participation and Inclusion, Bloorview Research Institute, YMCA.

**Client and family need:** Youth with disabilities participate in less physical activity which can lead to serious negative health outcomes and reduced quality of life. They also experience less access to sport, fitness and recreation opportunities and there is a critical need for health promotion interventions.

**Vision and impact statement:** This third phase of the project aims to implement and evaluate a health promotion program protocol designed by and for adolescents with physical disabilities with our partners at YMCA and Children's Treatment Centres.

**Deliverables:** Intervention pilot/study and stakeholder engagement workshop.

**Funding:** \$20,000

## 17. Understanding the real-world effectiveness of augmentative and alternative communication (AAC) for students in school activity settings

**Year:** 2

**Contributors:** Steve Ryan (Senior Scientist), Anne Marie Renzoni (OT), Tracy Shepherd (SLP), Anna Oh (Research Assistant), Liisa Smith (TDSB), Gail Ozols (York Catholic DSB), and Dianne Parr (Hamilton-Wentworth DSB/Ontario Council for Exceptional Children (OCEC)).

**Programs/organizations:** Bloorview Research Institute, Participation and Inclusion program, Centralized Equipment Pool and Toronto District, York Catholic District and Hamilton Wentworth School Boards.

**Client and family need:** We know little about the impact of AAC interventions on the activities and participation of young people with AAC needs. Sound ways are needed to measure these real world outcomes in a variety of settings including schools.

**Vision and impact statement:** The goal of this project is to advance the development of the Functional Impact of AAC (FIACC-E) questionnaire. This educator-report questionnaire will ultimately help AAC and school-based professionals to learn more about functioning and facilitators/barriers for meaningful participation in students with AAC needs.

**Deliverables:** Availability of the FIAAC-E measure/manual on Flintbox website, presentation of a webinar for AAC and school-based professionals across Canada, and presentation at the Council for Exceptional Children Convention.

**Funding:** \$20,000

## **18. Umbrella review to move evidence to practice: using a transition framework to enable youth with disabilities to achieve desired adult life outcomes**

**Year: 1**

**Contributors:** Carolyn MacDougall (OT), Nadia Niles-Campbell (OT), Gillian King (Scientist), Laura Hartman (Post-Doctoral Fellow), Matt Freeman (PhD student), Mina Abdallay (Youth Leader), Ruma Achrekar (Family Leader), Diana McCauley (Manager, Employment Services), Gillian Parekh (Research Coordinator), Paul Smith (Family Leader).

**Programs/organizations:** Participation and Inclusion program, Bloorview Research Institute, School of Rehabilitation Science at McMaster University, Spinal Cord Injury Ontario, Toronto District School Board, other community partner agencies.

**Client and family need:** Youth with disabilities and their families report inadequate support as they prepare for adulthood and face inequality in educational attainment, employment, income, housing, community participation and relationships compared to citizens without disabilities.

**Vision and impact statement:** This team is building a framework of services and information which youth/families can customize and use over multiple years (e.g., grades 9-12) as they engage with services at Holland Bloorview and the community collaborating to help achieving their adult life expectations.

**Deliverables:** Umbrella review of research that facilitate youth transition into adulthood.

**Funding:** \$8,500