



Centre for Leadership

Through unparalleled partnerships, the Centre for Leadership will support the co-creation and implementation of solutions for the most meaningful and healthy futures for all children, youth, families

2019-20 Centre for Leadership funded projects

We are excited to share the list of projects selected for 2019-20 Centre for Leadership funding that will accelerate our No Boundaries strategic plan impact areas of discover for action, personalize pathways and connect the system.

Solutions in action:

1. Move and Connect: Group-based active rehabilitation intervention for youth with concussion

Contributors: Andrea Hickling (Occupational Therapist [OT]), Kim Moody (Physiotherapist [PT]), Shannon Scratch (Clinician Scientist), Nick Joachimides (Clinical Manager), Christine Providenza (Knowledge Translation Specialist [KTS]), Nick Reed (Senior Clinician Scientist), Katie Mah (PhD Candidate), Heidi Schwellnus (Collaborative Practice), Emma DiLoreto (Youth Advisor), Heather DiLoreto (Parent Advisor).

Client and family need: Persistent post-concussion symptoms can include physical, cognitive and emotional challenges. Current care in the Persistent Concussion Clinic at Holland Bloorview is to provide individualized but not group exercise programs. Research has shown the benefit of active rehabilitation approach and group-based programs, however these are not currently developed or evaluated for youth with persistent post-concussion symptoms.

Objective: The overall objective of this project is to develop a protocol for a group based active rehabilitation intervention (Move and Connect) and pilot this initiative with two groups of youth participants with persistent concussion.

Deliverables: Move and Connect group protocol, testing of Move and Connect with 16 youth with persistent concussion symptoms.

Funding: \$13,600

2. Validating the Family Needs Questionnaire for pediatric rehabilitation

Contributors: Caron Gan (Family Therapist, Clinical Investigator), Virginia Wright (Senior Scientist), Jean Hammond (Family Partnership Specialist), Louise Rudden (Nurse Practitioner [NP]), Dagmara Urbanowicz (Social Worker), Barb Fishbein-Germon (Social Worker), Pam Green (NP), Dilshad Kassam-Lallani (NP), Julie Chiba Branson (Clinical Manager), Marie Hooper (Parent Advisor), Irene Simpson (Clinical Manager), Christine Chow (e-Developer).

Client and family need: There is a lack of validated tools to assess family needs in pediatric rehabilitation practice that makes it challenging for clinicians to know what is important to families in the rehabilitation process. Parents of children with disabilities can find it difficult to fully know or share their needs, to improve family functioning and the well-being of the child.

Objective: Building off the previous success of the Family Needs Questionnaire Pediatric Version (FNQ-P) for families of a children with an acquired brain injury the team plans to adapt and create the Family Needs Questionnaire for Pediatric Rehabilitation (FNQ-PR) to make it applicable to other pediatric rehabilitation populations.

Deliverables: FNQ-PR digital product; user manual and scoring guidelines; validation of the FNQ-PR with 80-100 families.

Funding: \$19,800

3. Home-based baby constraint induced movement therapy

Contributors: Sophie Lam-Damji (OT), Sibel Cicek (Parent Team Member), Christie Welch (OT), Julie Chiba Branson (Clinical Manager), Darcy Fehlings (Physician Scientist), Karen Ward (Clinical Manager), Paige Church (Physician, Sunnybrook), Rudaina Banihani (Physician, Sunnybrook), Maureen Luther (PT, Sunnybrook).

Client and family need: Cerebral palsy is one of the most common childhood physical disabilities and 40% of these children experience significant arm and hand impairment. A recent randomized study from Sweden showed home-based constraint induced movement therapy as an effective intervention when provided during the first year of life leading to improved arm and hand function. Despite evidence for baby constraint induced movement therapy, it is not currently being provided in Canada.

Objective: The team is aiming to adapt Sweden's baby constraint induced movement therapy home program and test feasibility and impact in a community partner consultation care pathway.

Deliverables: Baby constraint therapy education module, baby constraint community partner consultation care pathway.

Funding: \$20,000

4. Botley's Bootle Blast: Overcoming barriers to home use for children and families with motor therapy goals

Contributors: Elaine Biddiss (Scientist), Ajmal Khan (Research Engineer), Alexander Hodge (Games Developer), Daniela Chan-Viquez (PhD Student), Linda Fay (OT), Darcy Fehlings (Physician Scientist), Sharon Wong (Commercialization Director), Joanne Wincentak (Knowledge Broker), Parent and youth advisors.

Client and family need: Eight years ago, families and clinicians at Holland Bloorview asked: Can we use video games to create fun and effective opportunities for motor therapy for children with cerebral palsy? The project team has worked in partnership with families and clinicians to develop Botley's Bootle Blast (BBB), a video game for hand-arm therapy. BBB was designed to overcome limitations of existing technologies used for hand-arm therapy including lack of feedback and inability to target therapy goals.

Objective: To develop BBB version 2 and integrate a new method for movement tracking using webcams, test the usability of BBB with webcam movement tracking and test the use and acceptability of the new version in three families' homes.

Deliverables: Version 2 of Botley's Bootle Blast with webcam, testing with 3 families

Funding: \$19,800

5. Putting positive weight-related conversations into practice: Driving the uptake of a strengths-based Knowledge Translation (KT) Casebook in a nursing context

Contributors: Amy McPherson (Senior Scientist), Christine Provvidenza (KTS), Catharine Petta (Registered Nurse [RN]), Louise Rudden (NP), Darlene Hubley (Educator), Lorry Chen (Registered Dietitian), Kim Krog (Collaborative Practice), Brendon Goodman (Obesity Canada member); Revi Bonder (Research Assistant), Family Advisors.

Client and family need: 1 in 3 Canadian children experience overweight or obesity and children with disabilities have significantly higher obesity rates, reducing mobility and independence, and increasing risks of additional health conditions. Overweight and obesity are sensitive topics to discuss and healthcare professionals (HCPs) report many barriers to raising the topic, including lack of training, confidence and resources.

Objective: Building off the previous success of co-creating the KT casebook in 2018 the team plans to co-create an implementation plan with nurses to integrate the casebook into care in a feasible and acceptable way, execute and evaluate the casebook implementation plan across care settings and identify strategies to ensure sustained casebook use at the individual and organizational level

Deliverables: Implementation process, training simulations, 10 trained casebook champions, testing and evaluation of casebook in practice

Funding: \$20,000

Co-creating personalized solutions

6. Mental health and wellness needs of young adults with spina bifida

Contributors: Andrea Snider (Psychologist), Amy McPherson (Senior Scientist), Dilshad Kassam-Lallani (NP), Shauna Beaudoin (Hydrocephalus Canada), Melissa Thorne (youth facilitator), Paige Church (Physician, Sunnybrook), Steve Kean (Hydrocephalus Canada), Laura Booth (Adult with Spina Bifida).

Client and family need: Young people with disabilities are at high risk for mental health concerns including anxiety, depression, and social isolation. Research has shown that 78.7% of the adults with spina bifida report psychological concerns, including depression, anxiety, poor self-esteem, relationship concerns, and loneliness. However, there is little research and support for mental health in this high-risk population.

Objective: The main objectives of project is to explore existing literature on communication best practices around mental health in paediatric health care settings and collaborate with parents and young adults with SB how the results of the literature review can be applied to a rehabilitation setting. The hope is with more effective support in our clinic, youth will be better equipped to cope with challenges as they transition to adult life.

Deliverables: Scoping review on best practices for mental health in paediatric health care, two engagement workshops with 20 young adults with spina bifida, knowledge translation activities.

Funding: \$16,800

7. R2Play: Co-creating a simulated sports environment to support return-to-play decision-making following youth concussion

Contributors: Shannon Scratch (Clinician Scientist), Elaine Biddiss (Scientist), Nick Reed (Senior Clinician Scientist), Virginia Wright (Senior Scientist), Stephanie McFarland (OT), Ajmal Khan (Engineer), Alexander Hodge (Games developer), Christine Provvienza (KT Specialist), Sharon Wong (Director Commercialization), Ali Mojdeh (PhD Student), Charlie Giffin (Community Coach Advisor), Kathy Leeder (Parent advisor).

Client and family need: Rowan's Law mandated medical clearance prior to "return to play" (RtoP) for youth athletes with concussion. However, there are no evidence-based standards for making RtoP assessments and current practice relies on self-report and a series of single-task assessments that fails to consider the multitask demands of sport which simultaneously challenge cognitive, sensory, physical and psychosocial skills.

Objective: Our goal is to co-create a testing protocol (R2Play) that contains multitask assessment to assist in return-to-play decision-making following a concussion at Holland Bloorview and clinics across Canada and internationally.

Deliverables: Stakeholder needs analysis, 3 co-creation workshops, R2Play protocol, testing with 16 youth with concussion.

Funding: \$20,000

8. Designing a new process of fabricating paediatric prostheses using digital technologies

Contributors: Jan Andrysek (Senior Scientist), Sandra Ramdial (Prosthetist, Clinical Manager), Kerri Kelland (PT), Ms. Elaine Ouellette (Prosthetic Resident), Calvin Ngan (Engineer).

Client and family need: The Orthotics and Prosthetics program provides custom orthoses and prostheses to clients across the lifespan with clinicians participating in approximately 4500 client visits each year. Traditionally, a prosthesis is made by capturing the shape of the residual limb using plaster. This process is costly in terms of physical materials and time requirements for clients, families and clinicians. Additionally, the process of applying plaster can be uncomfortable or distressing for young clients. Evidence suggests new technologies reduce time and material resources used in prosthetic practice and improve the overall client experience.

Objective: To investigate an appropriate scanner that can effectively and efficiently capture the shape of paediatric residual limbs, to design a new clinical method and workflow for digitally capturing residual limbs, to compare the time, materials, and overall client and family experience between conventional capture and digital scanning methods

Deliverables: A new clinical process for digitally capturing residual limbs in a paediatric population; comparison study of conventional plaster-based shape capture method to digital method

Funding: \$20,000

9. Increasing intervention impact: Enhancing the parent learning experience in the Social ABCs through an innovative video resource

Contributors: Jessica Brian (Clinician Scientist), Abbie Solish (Psychologist), Erin Dowds (Student), Kate Bernardi (Student), Sara Daoud (Student), Jonathan Leef (Student), Kate Perry (Speech Language Pathologist [SLP]), Martha Pilkington (Clinical Manager), Ian Roth (SLP), Greg Vanden Kroonenberg (Multimedia Support), Susan Cosgrove (Family Leader), Adrienne Zarem (Family Leader).

Client and family need: Holland Bloorview in collaboration with IWK in Halifax developed the Social ABCs parent-mediated intervention for toddlers with autism spectrum disorder. Despite good progress and parent satisfaction the 6-week program is not sufficient for some families to fully consolidate the strategies and these parents have requested additional support.

Objective: To increase the impact of the Social ABCs Group model the team will develop a video resource that parents can access between coaching sessions to enhance their learning. The team will work with project partners to co-create a series of user-friendly videos that demonstrate key techniques, common challenges and trouble-shooting strategies.

Deliverables: Parent education video series, pilot with 8 families.

Funding: \$19,000

Solutions connecting the system:

10. HBCompass: Co-creating an app to help families navigate the services system

Contributors: Azadeh Kushki (Scientist), Melanie Penner (Clinician Scientist), Salina Eldon (Research Coordinator), Cathy Petta (RN), Pam Green (NP), Gideon Sheps (Family Leader), Melissa Ngo (Family Support Specialist), Eric Wan (Software Developer), Sharon Wong (Commercialization Director).

Client and family need: Individuals with disabilities often require a range of services and interventions throughout their life. Our services system is fragmented, highly complex, and challenging to navigate for families, making it difficult to find timely and quality services that meet their unique needs.

Objective: In the second year of funding the HBCompass prototype will be tested with Families Leaders to identify and mitigate usability and technical issues prior to launch. The team will then implement and publicly launch HBCompass for families which includes a fully-functioning version and partnerships to ensure a strong user-base and critical capacity.

Deliverables: 3 co-creation workshops with families, evaluation study with 20 families, external launch of HBCompass

Funding: \$20,000

11. Does foolish playing enhance young people's wellbeing? A qualitative study of hospital-based clown practices

Contributors: Julia Gray (Postdoctoral Fellow), Helen Donnelly (Therapeutic Clown), Louise Kinross (Family Leader), Suzette Araujo (Therapeutic Clown), C.J. Curran (Transition Director), Barbara Gibson (Senior Scientist).

Client and family need: This study aims to identify the ways therapeutic clowns engage with and support the wellbeing of kids with disabilities in the hospital. Research regarding clowns in children's hospitals, often focuses on the ways these practices reduce depression and anxiety for children, as well as supporting other medical and clinical practices. Research that focuses on rehabilitation settings and children with disabilities specifically, as well as the practice of therapeutic clowns itself, is very limited.

Objective: We will investigate how playful, imaginative and "foolish" performance-based interactions impact children's experiences of wellbeing in the context of hospitalization. These findings will enhance understanding how the mechanisms underpinning clown practices support childhood wellbeing and can inform clinical practices more broadly, with the intent to implement solutions for improving children's wellbeing.

Deliverables: Study of clown practice with 30 children and parent, submission of two peer reviewed papers.

Funding: \$20,000

12. Supporting students by enhancing educator knowledge about acquired brain injury

Contributors: Shannon Scratch (Clinician Scientist), Christine Providenza (KTS), Naomi Smith (Research Coordinator), Sara Stevens (Psychologist), Alicia Brown (Family Advisor), Anne Hunt (Clinical Manager), Lisa Kakonge (SLP), Boey Ho (Youth Leader, SLP), Linda Ward (Principal, Bloorview School), Ruth Wilcock (Exec. Director, Ontario Brain Injury Association), Sheila Bennett (Educator, Brock University), Rhonda Martinussen (Educator, Ontario Institute for Studies in Education).

Client and family need: Acquired Brain Injury is the leading cause of disability among children but educators hold misconceptions, have little knowledge, and are ill-prepared to support children with ABI in the classroom. There is an opportunity to improve school reintegration of children with acquired brain injury to address observed cognitive, physical, behavioural, and emotional difficulties through improved support, collaboration and education for educators.

Objective: The purpose of year 3 is to complete the build of a user-informed eLearning module to enhance capacity, knowledge, and confidence of educators to support students with ABI in the classroom. Phase III project objectives: include completing eLearning module build; usability testing with 12 educators; survey to scope the need for accompanying resources to the eLearning module, ethics submissions for future pilot sites; and outreach to educator champions and stakeholders.

Deliverables: eLearning module for educators, testing of tool with 12 educators, knowledge translation activities.

Funding: \$20,000

13. Evaluating a new solution to improve current physiotherapy intervention in children and youth with acquired brain injury: Does brain stimulation plus physiotherapy equal better motor recovery?

Contributors: Jennifer Ryan (PT, PhD student), Virginia Wright (Senior Scientist), Deryk Beal (Clinician Scientist), Kelly Brewer (PT), Nicole Cavanaugh (PT), Viola Cheng (PT), Gail Kirkwood (PT), Tracy Lee (PT), Tricia Martin (PTA), Greg Steffler (PTA), Fraser Stephenson (Student).

Client and family need: Acquired brain injury (ABI) is the leading cause of disability in Canadian children. Despite gains children make during intensive rehabilitation, the long-term impact of ABI influence their future development, participation, and physical activity, and adversely affect their health and wellbeing. There is an opportunity to maximize motor recovery and associated functional outcomes by implementing novel treatment solutions within traditional therapies.

Objective: The project will test the effectiveness of transcranial direct current stimulation (tDCS) as a pre-treatment addition to intensive physiotherapy for children in the inpatient ABI rehab program. The project aims to answer if children with ABI who receive real tDCS with intensive physiotherapy recover gross motor function faster and to a higher degree than children who receive sham-control tDCS and if children tolerate the tDCS intervention.

Deliverables: Testing with 10 children with moderate to severe ABI, conference presentation, peer-reviewed journal article.

Funding: \$20,000

14. “Lost in time”: Updating the content and clinical accessibility of the Prosthetic Upper Limb Functional Index

Contributors: Sandra Ramdial (Prosthetist, Clinical Manager), Lisa Artero (Occupational Therapist), Virginia Wright (Senior Scientist), Kristen Matthews (Prosthetist), Neil Ready (Prosthetist & Orthotist), Christine Chow (e-Developer), Family Leaders.

Client and family need: The Prosthetic Upper Limb Functional Index (PUFI) was created 20 years at Holland Bloorview and was designed to give a picture of a child’s real-world prosthesis use. In the last five years, technical issues and not updating the content to current day advancements have caused the PUFI’s gradual abandonment by clinicians internationally despite its positive impact on prosthetic rehabilitation.

Objective: The team aims to update the PUFI to make it more relevant to present-day prosthetic users and enhance its international applicability. We will develop and testing an online PUFI with 10 clients and families that will allow them to efficiently access via a secure web-based portal.

Deliverables: Updated Prosthetic Upper Limb Functional Index (PUFI), testing with 10 clients and families

Funding: \$18,500

Centre Led Initiatives enhancing knowledge, skills and tools in solution design, implementation and learning organization practices at Holland Bloorview

15. Knowledge Translation Facilitator Network (KTFN) year four

Partnerships: Evidence to Care (EtC), Client and Family Integrated Care (CFIC).

Purpose: We provide 18 hours on in class training to members of Centre for Leadership, Research Family Advisory Committee, Family Advisory Committee and other Holland Bloorview teams to enhance knowledge translation competencies and skills. This leads to enhanced and more effective knowledge translation goals and activities across Holland Bloorview.

Deliverables: 12 new staff and family leaders trained as Knowledge Translation Facilitators, this will bring our facilitator network to 42 members.

Funding: \$4,000

16. Launching technological solutions beyond Holland Bloorview

Partnerships: Commercialization, Programs and Services, Bloorview Research Institute, EtC, CFIC.

Purpose: Teams have incredible expertise in designing new technology (e.g. Project LEApp, HBCompass) but we lack knowledge and skills in launching these solutions to make a global impact. In direct partnership with Commercialization we will support collaboration and capacity building with external experts in launching successful technological solutions beyond Holland Bloorview.

Deliverables: Consultations between internal and external experts; strategies and activities to support external technology launch.

Funding: \$10,000

17. Implementation practices at Holland Bloorview and in the system

Partnerships: Programs & Services, Collaborative Practice, Bloorview Research Institute, Teaching and Learning (T&L), EtC, CFIC.

Purpose: Our aim is to collaborate with teams across Holland Bloorview completing intervention projects (e.g. Meditech Expanse, Virtual Care, Concussion Education) and collect strategies, practices and challenges with implementation of solutions in a healthcare setting. We will also complete an external scan of implementation practices across the system.

Deliverables: Interviews with 15-20 teams across Holland Bloorview, report on findings and recommendations, knowledge mobilization activities.

Funding: \$5,000

18. Supporting research, program evaluation and quality improvement planning

Partnerships: Research Ethics Board, T&L, EtC, Quality and Safety, Programs and Services.

Purpose: There is a lack of knowledge and tools among staff and families related to distinguishing between research, quality improvement and program evaluation activities. We plan to validate, train and implement a decision making tool to support teams.

Deliverables: Training and implementation of a decision support tool with 40 teams across Holland Bloorview.