Centre for Leadership

In 2021-22 for the first time the Centre for Leadership put out a call for applications with priorities selected by clients, families, healthcare providers and leaders with the intent to enhance integration and clinical, research and education impact. Below are the three new Centre for Leadership projects that will research and expand our knowledge in two priority areas:

Investigating social determinants of health and health inequities, and the impact on client and family access to care, care experiences, and clinical outcomes

Project 1: Understanding Health Care Experiences of Racialized Youth with Disabilities, their Caregivers, and the Health Providers Who Serve Them — Services, Access, Navigation, and Interpretation (SANI project).
Team: Dr. Fiona Moola (Scientist), Dr. Timothy Ross (Scientist), Nivatha Moothathamby (Researcher), Methuna Naganathan (Researcher), Sydney Campbell (Research Assistant), Dilshad Kassam-Lallani (Nurse Practitioner), Dr. Aliya Amarshi (Post Doc Fellow, Ryerson University)
Research objectives: 1) Explore the issues and challenges that racialized youth with disabilities and their parents experience while accessing and receiving pediatric health care services; 2) Describe the youths' and parents' process of navigating the pediatric health care system; 3) Learn what childhood disability means to racialized youth with disabilities and their caregivers; and 4) Describe healthcare staff experiences of engaging racialized clients and families.
Funding: $50,000

Investigating the impact of the COVID-19 pandemic on children, youth and families

Project 2: Well Being, COVID 19, and Resilience in Youth with Disabilities
Team: Dr. Shannon Scratch (Scientist), Dr. Amy McPherson (Senior Scientist), Brendan Lam (Research Assistant)
Research objectives: The goal of this project is to characterize any positive experiences emerging from the COVID 19 pandemic for youth with disabilities and their families, using a strengths based approach; objective 1: Explore the experiences of children and their parents during COVID-19 and where they have been able to thrive; objective 2: To understand what factors contribute to well being and resilience in youth with disabilities.
Funding: $50,000

Project 3: Kids, Virtual Care and the COVID-19 pandemic: learning from our experiences
Team: Dr. Virginia Wright (Senior Scientist), Dr. Sally Lindsay (Senior Scientist), Andrea MacDonald (Operations Manager), Alifa Khan (Family Leader), Carly Cermak (SLP, PhD student), Gloria Lee (Research Manager), Chuanlin Zhou (Research Student), Samantha Alfaro (Youth Advisor) .
Research questions: 1. What are the positive and negative features of virtual care in a real-world pediatric rehabilitation setting in rapid response to care restrictions imposed by the COVID-19 Pandemic? How does the focus and content sessions carried out by SLP, OT or PT compare to in-person sessions in goal-based sessions? What aspects of virtual care need to be changed/improved to make it viable and fully acceptable for integration into everyday practice?
Funding: $50,000

Implementation of solutions: In addition we are supporting 11 projects that were significantly impacted by the COVID 19 pandemic in 2020-21 so they can complete their project activities and deliverables to advance research and solution implementation at Holland Bloorview.

4. Zippy's Friends a resiliency and mental health support program for children and youth with disability

Contributors: Heidi Schwellnus (Collaborative Practice Leader), Jean Hammond (Family Partner Specialist), Lorraine Millett (Zippy's Friends), Ishanee Jahagirdar (OT), Alana Stancer, Jessica Bellisario

Client and family need: The Ontario Child Health Study reported that 11% of children in schools have identified mental health concerns and Dr. Peter Szatmari (CAMH, SickKids) indicated that this is significantly higher among children with disabilities.

Objective: The Zippy's' Friends program has been adapted for children and youth with disability and is being implemented and evaluated to capture how the program fosters coping and social skills as precursors to resiliency. Zippy's Friends is a foundational step to address resiliency at Holland Bloorview and will set the groundwork for future resiliency programs that will contribute to the overall vision of the Child and Youth Mental Health initiative "Enabling a child's healthy mind, body and spirit".

Deliverables: Implementation and evaluation of Zippy's Friends with up to 20 participants and their caregivers; national conference presentation

Funding: $5,000

5. Enhancing concussion recovery through Move & Connect a rehab group based exercise program

Contributors: Andrea Hickling (OT), Kim Moody (PT), Shannon Scratch (Clinician Scientist), Nick Joachimides (Clinical Manager), Christine Provvidenza (Knowledge Translation Lead), 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 provides individualized active rehabilitation but not group exercise programs. The Move & Connect intervention is a 6-week low intensity exercise program conducted in a group-based setting designed for youth with persistent symptoms post-concussion to learn new skills to manage symptoms in everyday life and meet others with similar experiences.

Objective: The team will conduct testing of the Move & Connect program using measures of quality of life and self-efficacy as well as interviewing participants about their experiences with the intervention. Our team aims to personalize pathways by merging the benefits of targeted, individualized low-intensity exercise programs with the advantages of social group support in order to foster self-efficacy, feelings of success, and help youth with persistent symptoms post-concussion return to meaningful activities.

Deliverables: Complete testing of Move and Connect with 48 youth with prolonged symptoms post-concussion; develop an instructional support guide to help with scale and spread the Move & Connect program.

Funding: $12,700

6. Connecting caregivers to share knowledge, support and cope after their child's acquired brain

Contributors: Sara Stevens (Neuropsychologist), Mary Stewart (Neuropsychologist), Shannon Scratch (Clinician Scientist, Neuropsychologist) Melissa Ngo (Family Support Specialist), Caron Gan (Clinician Investigator), Lies Ferriman (Family Leader)

Client and family need: There are significant levels of burden and family stress reported by caregivers following their child's acquired brain injury (ABI) yet essential needs such as information about ABI, social support, and peer support are often reported to be unmet.

Objective: The team aims to implement and evaluate Caregivers Connecting after ABI (CCABI), an educational and psychosocial group for caregivers of children with ABI. The program provides a combination of ABI education, psychosocial support, and coping strategies through teaching and open discussion formats. The evaluation will utilize one-to-one interviews to gather in-depth descriptions of caregivers' experiences with the CCABI group. This project supports Holland Bloorview's Mental Health Initiative by providing resources, educational opportunities and support for families and caregivers, ultimately impacting their own mental wellbeing and their child's care.

Deliverables: Completion of a research study of CCABI group and development of a facilitator clinical guidebook.

Funding: $6,600

7. Maximizing use of Augmentative & Alternative Communication systems for children in schools

Contributors: Tracy Shepherd (Clinical Educator, SLP), Anne Marie Renzoni (Clinical Educator, OT), Sheri McClement (OT), Christine Matthews (SLP), Virginia Wright (Sen Scientist), Steve Ryan (Adj Scientist), Gloria Lee (Research Manager), Sarah Naumann (Bloorview School Authority), Lisa Archibald (Professor, UWO, London) and B. Roberts Santa-Rossa (John McGivney Children Centre, Windsor)

Client and family need: Many children with communication and speech difficulties benefit from AAC systems, yet in the school setting children and teachers run into many challenges with successful use of these devices. This can lead to difficulty in academic achievement, vocational outcomes, social isolation and marginalization.

Objective: The Functional Impact of Augmentative and Alternative Communication Educator (FIAAC-E) measure is designed to capture how effectively a child is using the AAC system in the classroom. The team will pilot test the use of the FIAAC-E within three Ontario treatment centre schools with the ultimate goal of achieving a viable approach to FIAAC-E implementation in the classroom and corresponding improvements in children's AAC use.

Deliverables: Development of FIAAC-E administration and scoring guide and user process; evaluation in the classroom context of the FIAAC-E's strengths and opportunities for improvement, and creation of an implementation support plan.

Funding: $29,700

8. Getting the Prosthetic Upper Extremity Functional Index (PUFI-2) into clinical use

Contributors: Sandra Ramdial (Prosthetist, Manager), Lisa Artero (Occupational Therapist), Virginia Wright (Senior Scientist), Kathryn Parker (Teaching and Learning), Meghan Donohue (Family Leader), Ashley Ogilivie (interviewer) and Gloria Lee (Project Manager)

Client and family need: Many clients with an upper limb absence have challenges performing everyday activities like tying shoelaces, cutting paper with scissors, climbing on playground equipment, opening snack packages, cutting food, and holding a smartphone or tablet. The PUFI measure was designed to capture prosthesis use but was 20 years out of date and not sensitive to cultural and environmental differences. With extensive input from children who use an upper limb prosthesis, parents and international clinical partners, we created the updated PUFI-2 to address the shortcomings of the previous version.

Objective: The team is developing an implementation map and training tools to support the new PUFI-2's consistent and successful use here at Holland Bloorview and with our clinical partners nationally and internationally.

Deliverables: Implementation of the PUFI-2 at Holland Bloorview and three partner sites; refinement of implementation process and training materials to support meaningful clinical use with clients across an ever-expanding international reach.

Funding: $7,300

9. Relaxed, recharged and ready: Empowering children and youth with autism spectrum disorder to co-create their personalized care plan for arousal regulation

Contributors: Christie Welch (Postdoctoral Fellow), Melanie Penner (Physician, Clinician Scientist), Martha Pilkington (Manager), Angela Pommells (Family Leader), Clementine Pirlot (Self Advocate), Helene Polatjko (Professor, UofT)

Client and family need: Many children and youth with autism (or autistic children and youth) describe difficulties with arousal regulation and staying calm which can lead to loss of composure, being overwhelmed, exhaustion or a feeling of being “stuck” and seriously impacts performance in school, relationships, and ability to gain employment.

Objective: The team will to develop a personalized care plan tool that enables children and youth with autism to better understand, direct and manage their own arousal regulation. In addition the team aims to raise public awareness of arousal regulation in autism.

Deliverables: Prototype of a personalized care plan tool and development of a public awareness video.

Funding: $5,600

10. PRISM Beats: an accessible DJ app for children with motor challenges to make their own music

Contributors: Fanny Hotzé (Pediatric Assistive Technology Specialist), Andrea Lamont (Music Therapist), Eunice Kang (MT), Julie Chiba Branson (Manager), Annie Lopez (Assistive Technology Consultant), Joanne Downing (Family Leader), Matthew Downing (Youth Leader), Fiona Moola (Scientist)

Client and family need: Making music can enhance feelings of self-confidence and independence, improve physical, cognitive, and communication skills, and augment quality of life. Traditionally, access to music activities can be extremely challenging or even impossible for children and youth with moderate or severe motor challenges.

Objective: The switch-accessible DJ app PRISM Beats allows a child to trigger specific sounds either by using their switch or via direct access. The first PRISM Beats prototype has been used by a variety of children and demonstrated tremendous potential to enhance participation in music-making activities. The team will design and test a more user-friendly and versatile version of the PRISM Beats app that will enable children to independently participate in creative musical expression.

Deliverables: A user-friendly switch-accessible DJ mobile application; education and training materials for users of PRISM Beats, parents, and clinicians.

Funding: $14,500

11. R2Play a simulated sports environment to support return-to-play after youth concussion

Contributors: Shannon Scratch (Clinician Scientist), Elaine Biddiss (Scientist), Virginia Wright (Senior Scientist), Nick Reed (Scientist), Christine Provvidenza (KT Lead), Stephanie McFarland (OT), Kathy Leeder (Family Leader), James Murphy (Manager), Sharon Wong (Commercial.), Alexander Hodge (Game Developer), Ajmal Khan (Engineer), Danielle Duplessis, Ali Modjeh and Emily Lam (Trainees)

Client and family need: Rowan's Law mandated medical clearance prior to "return to play" for youth athletes with concussion. However, there are no evidence-based standards for making return to play assessments and current practice relies on self-report and a series of single-task assessments that fail 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, clinics across Canada and internationally. R2Play will be the first solution of its kind with international application that extends beyond pediatric rehabilitation to professional athletes and military personnel and creates discover for action through integration of research, care and technology.

Deliverables: Design and testing of clinician interface in the form of a mobile application to efficiently administer and document the R2Play protocol and personalize the assessment for 10 youth with concussion.

Funding: $6,700

12. 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 (KT Lead), Catharine Petta (Registered Nurse [RN]), Louise Rudden (NP), Darlene Hubley (Educator), Lorry Chen (Registered Dietitian), Kim Krog (Collaborative Practice), Brenndon 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: To build upon the success of co-creating the KT casebook and the completion of an earlier implementation study within the autism spectrum disorder context, the team plans to implement the KT Casebook with healthcare providers (i.e. nurses, physicians, occupational therapists and physiotherapists) across different disability contexts. The team will work with the healthcare providers to integrate the Casebook into care in way that is a feasible for them. Implementation supports will be co-created with the healthcare providers, and the execution of the KT Casebook implementation plan will be evaluated. Information from this study will be used to inform future conversations to promote the sustained use of the KT Casebook at the individual and organizational level.

Deliverables: Implementation process, training simulations, implementation supports, 10 trained casebook champions, test/evaluate casebook in practice

Funding: $4,400

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), Anna Tendera (Postdoctoral fellow), Puja Ahluwalia (PT), Kelly Brewer (PT), Nicole Cavanaugh (PT), Viola Cheng (PT), Alysha Ladha (MD), Tracy Lee (PT), Tricia Martin (PTA), Greg Steffler (PTA), Fraser Stephenson (PT), Tiffany Walpole (PTA).

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: $5,000

14. 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 education webinar and implementation videos.

Funding: $2,500