



Centre for Leadership

We are excited to share the 12 projects selected for 2020-21 Centre for Leadership funding that will accelerate discover for action and implementation of solutions.

- In 2020-21 we increased funding grants to a maximum of \$35,000 and dedicated 70% of program funding to test and implementation projects.
- These projects will support the most meaningful and healthy futures for children, youth and families in autism spectrum disorder, acquired brain injury, persistent pain, concussion, mental health and resiliency, caregiver support, music technology, prosthetics, augmentative and alternative communication and dentistry.

Implementing solutions at Holland Bloorview:



- Zippy's Friends a resiliency and mental health support program for children and youth with disability
- Enhancing concussion recovery through Move & Connect an active group based rehab program
- Using sensory experiences and virtual reality to reduce anxiety for children with autism spectrum disorder in the dentist office
- Connecting caregivers to share knowledge, support and cope after their child's acquired brain

Implementing solutions across the system:



- Expanding Social ABC's for children with autism spectrum disorder and their families across Canada
- Maximizing use of Augmentative & Alternative Communication systems by children in schools
- Getting the Prosthetic Upper Extremity Functional Index (PUFI-2) into clinical use

Designing solutions with children, youth and families



- Relaxed, recharged and ready: Empowering children and youth with autism spectrum disorder to co-create their personalized care plan for arousal regulation
- PRISM Beats an accessible DJ app for children with motor challenges to make their own music
- Testing magnetic brain stimulation to support recovery for youth with persistent pain symptoms
- Using R2Play a simulated sports environment to support return-to-play after youth concussion
- Introducing brain stimulation to promote helpful self-regulation behaviour in children with autism spectrum disorder

To learn more about the contributors, objectives and deliverables for all 12 projects please review pages 2-5



Implementing solutions at Holland Bloorview

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

Contributors: Heidi Schwellnus (Collaborative Practice Leader), Nancy Searl (CPL), Gillian King (Senior Scientist), Laura Hartman (Research Assoc.), Jean Hammond (Family Partner Specialist), Brian Mishara (Université du Québec à Montréal), Lorraine Millett (Zippy's Friends), Laura Thompson (OT), Ishanee Jahagirdar (OT), Marlee Bell (CDA), Mary Dunn (CDA) & Halla Fahmi (Psychometrist)

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; national conference presentation

Funding: \$20,000

2. Enhancing concussion recovery through Move & Connect an active group based rehab 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 at Holland Bloorview 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: \$33,000

3. Using sensory experiences and virtual reality to reduce anxiety for children with autism in the dentist office

Contributors: Molly Friedman (Dentist), Tanya Wishloff-Hunt (Manager), Cathy Petta (Registered Nurse), Azadeh Kushki (Scientist), and Salina Eldon (Research Manager)

Client and family need: Many children with autism have poorer oral health than their typically developing peers often due to challenging behaviours and high levels of anxiety around dental visits. Typical dental environment sensory experiences (e.g. noises, odors, lights, and invasion of personal space) and a lack of knowledge around what to expect at the visit contribute to anxiety for children with autism and often led to avoidance or reluctance to participate in important dental practices.

Objective: This project will design a sensory "snoezelen" environment and create a virtual reality solution to reduce anxiety as well as cost and time needed for children to feel more comfortable at dental appointments. Adaptations such as dimmed lighting, visual ceiling projections, music, weighted vests, and bean bag chairs will help create a more calming environment.

Deliverables: Implementation of a Snoezelen multisensory environment in the dental clinic rooms and design of a virtual reality desensitization experience.

Funding: \$20,000

4. 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 open-ended 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: \$10,000



Implementing solutions across the system

5. Expanding Social ABC's for children with autism and their families across Canada

Contributors: Jessica Brian (Clinician Scientist), Abbie Solish (Psychologist), Kate Bernardi (Research Coordinator), Erin Dowds (RC), Ian Roth (SLP), Sara Daoud (RC), Kate Perry (SLP), Stacey MacWilliam (IWK, Halifax), Sanne Jildera (Glenrose, Edmonton), Natalie Rugajs and Kristina Paul (Hamilton Health Sciences)

Client and family need: Holland Bloorview, in collaboration with IWK in Halifax, developed the Social ABC's parent-mediated intervention for toddlers with autism spectrum disorder. Social ABC's has been successful but needs training materials and coaching to support program spread, scale and maximize impact for children and families across Canada.

Objective: The project will develop and test a new training program along with a community of practice with trained coaches to promote ongoing growth and sustainability of the Social ABC's program.

Deliverables: Development of a Coaches' Manual and Social ABC's training package; implementation of Social ABC's training program at two national sites.

Funding: \$35,000

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

Contributors: Tracy Shepherd (Clinical Educator, SLP), Anne Marie Renzoni (Clinical Educator, OT), Sherri McClement (OT), Christine Matthews (SLP), Virginia Wright (Sen Scientist), Steve Ryan (Adj Scientist), Gloria Lee (Research Manager), Linda Ward (Bloorview School), Beth Dangerfield (Family Partner. Specialist), 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 and 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 the child is using the AAC system in the classroom. The team will co-design training materials with two Ontario treatment centres with the goal of FIACC-E implementation and improved AAC use in the classroom.

Deliverables: Development of digital version of FIAAC-E and administration guide; creation of an implementation support plan.

Funding: \$31,000

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

Contributors: Sandra Ramdial (Prosthetist, Clinical Manager), Lisa Artero (Occupational Therapist), Virginia Wright (Senior Scientist), Kathryn Parker (Teaching and Learning), Meghan Donohue (Family Leader)

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 was not sensitive to cultural and environmental differences. With the support of CfL funding in 2019/20 and 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: \$32,000



Designing solutions with children, youth & families

8. 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 Investigator), Martha Pilkington (Manager), Mitchell Golbeck (Self Advocate), Angela Pommells (Family Leader), Raya Shields (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: \$16,000

9. 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)

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: \$20,000

10. Testing magnetic brain stimulation to support recovery for youth with persistent pain symptoms

Contributors: Ardith Baerveldt (Psychologist), Sefi Kronenberg (Physician), Lori Palozzi (Nurse Practitioner), Melissa Joseph (Social Worker), Deryk Beal (Clinician Scientist), Lauryn Seguin (Youth Leader), Jodi Seguin (Parent)

Client and family need: Pediatric persistent pain is a significant problem associated with high health care utilization and approximately 5-8% of adolescents suffer from this condition. This persistent pain impacts their quality of life and functioning in academic, recreation and social activities.

Objective: Repetitive transcranial magnetic stimulation (rTMS) is a brain stimulation technique that is safe, innovative and economical and has been used to successfully reduce pain, anxiety and depression in adults but remains untested in youth with persistent pain. This solution may provide a new personalized solution for clinical services and transform how youth with persistent pain access and move through our health care system.

Deliverables: Feasibility study on whether this a tolerable and acceptable intervention for 24 youth with persistent pain symptoms.

Funding: \$20,000

11. Using 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: \$20,000

12. Introducing brain stimulation to promote helpful self-regulation behaviour in children with autism spectrum disorder

Contributors: Deryk Beal (Clinician-Scientist), Evdokia Anagnostou (Senior Clinician Scientist), Anna Tenders (Postdoctoral Fellow), Ishanee Jahagirdar (OT), Megan Lynch (OT), Angela Pommels (Family Leader), and Protibha Gupta (Family Leader)

Client and family need: For many children with autism spectrum disorder self-regulation of behaviour is a significant challenge and can lead to ineffective behavioural strategies with risk of self-harm, parental stress and social stigmatization. Children with autism, parents and caregivers have identified the need to establish interventions and support that promote regulation and reduce disruptive behaviours.

Objective: We will test if non-invasive repetitive transcranial magnetic stimulation (rTMS), which has been shown to be a safe and cost-effective intervention to promote helpful self-regulatory behaviour in young adults with ASD, is feasible and acceptable to children with ASD and their families. We expect rTMS to improve inhibitory skills, behaviour regulation and quality of life after treatment and to promote reorganization of the neural network for behaviour regulation.

Deliverables: Feasibility study on whether this a tolerable and acceptable therapy with 20 children with autism spectrum disorder.

Funding: \$20,000