



Centre for Leadership

In 2022-23 the Centre for Leadership is:

1. Launching five new solution projects supporting the most meaningful and healthy futures for all children, youth and families;
2. Continuing three clinical research projects investigating Holland Bloorview's strategic priority areas the impact of a) COVID-19 on children, youth and families and b) health inequities and impact of social determinants of health;
3. Continuing four solution projects that initiated work in 2021-22;
4. Launching a new knowledge mobilization fund to drive sharing and utilization of education and training

1. New solution design, testing and Implementation projects

1a. Becoming Friends: strengthening friendships and belonging of children and youth with disabilities through design and implementation of a holistic evidence-based framework

Team: Eric Smart PhD (OT), Gillian King PhD (Distinguished Senior Scientist), Anna Oh (Research Assistant), Heather Keating (Clinical Team Lead Transitions, Therapeutic Recreation, Life Skills), Steph DiMartino (Life Skills Coach); Melissa Thorne (Youth Facilitator), Mikayla Hjørngaard (Youth Leader), Holly Yip (Family Leader), Alex Neff (Coordinator, Planned Lifetime Advocacy Network); Daphne Schreiber (Researcher, March of Dimes Canada), Alana Armas, (Researcher, March of Dimes Canada), De-Lawrence Lamptey (PhD, Postdoc, York University).

Client/family Need: A parent at Holland Bloorview wrote publicly about her family's experience at the time of receiving a possible diagnosis for her son, showcasing the importance of friendship even in those earliest moments: "My husband asked, through silent tears: 'But will he still be able to run and jump and play with his friends?' At the time, we didn't question that [he] would have friends."

Objectives: The team will develop an accessible framework of Holland Bloorview friendship programs (e.g., Virtual Drop-Ins, Common Room, Life Skills Programs) and community programs to personalize pathways for social connections and friendships for each client.

Deliverables: 1. Holistic evidence-based framework for strengthening friendship, 2. Friendship program recommendations.

Funding: \$19,000



1b. Putting the play into accessible playgrounds: Program options for accessible playgrounds in education and health care settings

Team: Dr. Tim Ross (Scientist), Dr. Kelly Arbour-Nicitopoulos (Adjunct Scientist), Rebecca Vanderburgh (OT), Kerri Kelland (PT); Sarah Nauman (Bloorview School) Shalaine Sedres (Researcher), Iwan Mota (Family Leader), Melissa Ngo (Family Support Specialist), Dr. Shauna Kingsnorth (Manager, Evidence to Care).

Client/family Need: While there has been a recent shift toward building accessible playgrounds, little attention has been given to creating programming options that could help to leverage these play spaces and make them more fun and inclusive for kids with disabilities.

Objectives: Our team will listen to and voice the needs and desires of kids with disabilities, parents and professionals. We will prepare well-informed recommendations for developing accessible playground programming options to create more inclusive play opportunities, incorporate playground use into educational and clinical activities, and to help improve the quality of life of kids.

Deliverables: 1. Report of programming experiences, needs & preferences, strategies, and recommendation, 2. A half-day event with stakeholders to engage findings, resolve issues, identify research directions, and discuss the implementation of recommendations.

Funding: \$25,000



1c. R2Play getting youth back to sports safely: R2Play testing for youth post-concussion

Team: Dr. Shannon Scratch (Clinician Scientist, Neuropsychologist), Dr. Elaine Biddiss (Scientist); Dr. Virginia Wright (Senior Scientist), Dr. Nick Reed (Adjunct Scientist), Dr. Michael Hutchinson (Associate Professor UofT, Kinesiologist), Christine Provvienza (Knowledge Translation Specialist), Stephanie McFarland (OT), Heather & Emma Di Lorento (Parent and Family Advisors), Sharon Wong (Commercialization), James Murphy (Manager), Alexander Hodge (Games Developer), Ajmal Khan (Engineer), Josh Shore (PhD student), Danielle DuPlessis, Emily Lam, Andrea Hickling (Contributors)



Client/family need: Returning to sport post-concussion relies on self-reported symptoms, neurocognitive and exercise testing on single task assessment this does not consider multitask demands of sport in cognitive, sensory, physical, and psychosocial skills.

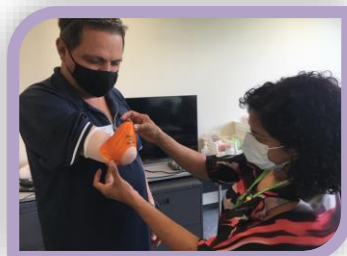
Objectives: R2Play is a dynamic multi-domain simulated sports environment that assesses physical, cognitive, sensory, and social skills simultaneously. In this third phase the focus is on testing and examining R2Play prototype feasibility with youth post-concussion to set up future internal and external implementation.

Deliverables: 1. Deliver a working R2Play system tested with both youth athletes' post-concussion and without a history of concussion, 2. develop a preliminary protocol for use of R2Play as a rehabilitation tool

Funding: \$25,000

1d. Personalizing prostheses: Diagnostic forearm for pediatric transradial prostheses

Team: Sandra Ramdial (Op. Manager Orthotics & Prosthetics), Dr. Jan Andrysek (Senior Scientist), Neil Ready (Certified Orthotist/Prosthetist), Elaine Ouellette (Certified Prosthetist), Kerri Kelland (Physiotherapist), Harry Sivasambu (Research Coordinator), Calvin Ngan (PhD Student)



Client/family need: Each child has a unique body and need in the design of their prosthesis. However, it is difficult to assess this until the prosthesis is made, at which point changes are difficult or even impossible to make.

Objectives: Develop an adjustable diagnostic forearm (ADF) to simulate the alignment, length, and function of the final prosthesis. This first of its kind device will find precise measurements and provide an opportunity for clients to be included in the design process and simulate a truer experience to their final prosthesis.

Deliverables: 1. Design and fabricate an ADF prototype, 2. Early pilot testing with clients/families

Funding: \$25,000

1e. Adopting Trexo: Designing of an adoption plan for new technology Trexo robotic walker in pediatric rehabilitation

Team: Dr. Virginia Wright (Senior Scientist), Stefanie Bradley (Doctoral trainee), Tom Chau (Senior Scientist), Shauna Kingsnorth (Evidence to Care manager), Jo-Anne Weltman (Physiotherapist SMILE Therapy), Andrea Norton (Physiotherapist, IET), Sharon Wong (Director Commercialization)



Client/family need: Previous learning experiences with robotic-assisted gait technologies in pediatric rehabilitation have shown that user experiences are complicated and individual to the child; understanding implementation and providing access to new technology in clinical programs is necessary and impactful for children, youth and their families.

Objectives: The Trexo mobile wearable exoskeleton gives children with functional mobility limitations the chance to walk with individualized powered assistance. This project will develop rehab adoption practices for Trexo use by physiotherapists to promote optimal functioning and fit of Trexo for each child to help them attain their personal mobility and participation goals in a rehab setting.

Deliverables: 1. Study the clinician experience within PT-based Trexo sessions, 2. Video-based training and treatment guide on PT best practices and adoption of the Trexo.

Funding: \$25,000



2. Clinical research investigations in strategic priority areas

2a. 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 Asst.), Dilshad Kassam-Lallani (Nurse Pract.), Dr. Aliya Amarshi (Post Doc, Ryerson).

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.

Deliverables: Complete arts based research data collection, host exhibit, develop impact report, research article.

Year 2 funding: \$18,000

2b. 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 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.

Deliverables: Complete survey and interview data collection and analysis; develop impact report and research article.

Year 2 funding: \$30,000

2c. 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), Celia –Marie Cassiani (Research Assistant).

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 of virtual sessions carried out by SLP, OT or PT compare to in-person sessions? What aspects of virtual care need to be changed/improved to make it viable and fully acceptable for integration into everyday practice?

Deliverables: Complete in session and interview research data collection, develop impact report, research article.

Year 2 funding: \$30,000

3. Implementation of solutions: In 2022-23 we will continue our support of four projects (2a-2d) and launch six-eight new projects focused on solution implementation that integrate clinical care, research and education.



3a. Connecting caregivers to share knowledge, support and cope after their child's acquired brain injury

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. This project supports Holland Bloorview's Mental Health Initiative by providing resources, educational opportunities and support for families and caregivers, impacting their mental wellbeing and their child's care.

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

Year 3 funding: \$3,400

3b. 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 schools with the goal of achieving a viable approach to FIAAC-E implementation in the classroom and improvements in children's AAC.

2022-23 Deliverables: Implementation and research evaluation in the classroom context of the FIAAC-E's strengths and opportunities, and creation of an implementation support plan, research article submission.

Year 3 Funding: \$14,700

3c. 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), 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 test and refine 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.

2022-23 Deliverables: Refine tool prototypes, conduct usability study for pediatric and adult versions of the tools.

Year 3 Funding: \$8,000

3d. 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), Sarah Holman (Research Assistant).

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.

2022-23 Deliverables: Complete online feedback surveys and co-creation workshops for switch-accessible DJ mobile application; new PRISM Beats prototype; education and training materials for users of PRISM Beats, parents, and clinicians.

Year 3 Funding: \$12,200

Coming soon!

Spring 2022: Knowledge mobilization and program evaluation

- The Centre for Leadership knowledge mobilization fund will offer small grants (up to \$5000) to enable development of educational and training materials to advance awareness and reach of best practices developed at Holland Bloorview. In addition the Centre for Leadership will pilot an integrated program evaluation of priority care and services. Both programs will be in partnership with Programs and Services and Evidence to Care.
- These new programs aims to launch in Spring 2022.
- The programs will fund eight to ten projects, the projects will be shared upon selection.