

ABSTRACT

POSTER TITLE: Go Far, Go Together: A Journey of Collaboration with Youth and Families for the READYorNot™ Brain-Based Disabilities Trial

AUTHOR(S)	Linda Nguyen¹, Kinga Pozniak², Kyle Chambers³, Barb Galuppi⁴, Nadilein Mahlberg⁴, Alicia Via-Dufresne Ley⁵, Shelley Doucet⁶, Ariane Marelli⁷, Adrienne Kovacs⁸, Khush Amaria⁹, Ronen Rozenblum¹⁰, Jan Willem Gorter⁴ on behalf of the READYorNot™ Brain-Based Disabilities Project Team.
INSTITUTION/ AFFILIATION(S)	¹ CanChild Centre for Childhood Disability Research, McMaster Autism Research Team, School of Rehabilitation Science, McMaster University, Hamilton, Ontario, Canada ² Parent Partner, Department of Pediatrics and CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, Ontario, Canada ³ Patient Partner, Ontario, Canada ⁴ Department of Pediatrics and CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, Ontario, Canada ⁵ Research Institute, McGill University Health Centre, Montreal, Québec, Canada ⁶ Department of Nursing and Health Sciences, University of New Brunswick, Saint John, New Brunswick, Canada ⁷ McGill Adult Unit for Congenital Heart Disease Excellence, Montreal, Québec, Canada ⁸ Knight Cardiovascular Institute, Oregon Health and Science University, Portland, Oregon, USA ⁹ CBT Associates of Toronto: Cognitive Behavioural Therapy Services, Toronto, Ontario, Canada ¹⁰ Department of Medicine, Brigham and Women's Hospital, Harvard Medical School, Boston, Massachusetts, USA
FUNDING SOURCE(S)	CHILD-BRIGHT Network, Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) initiative, Montreal Children's Hospital Foundation, McMaster University Faculty of Health Sciences, New Brunswick Health Research Foundation, McMaster Children's Hospital Foundation and Hamilton Health Sciences.

ABSTRACT

Background/Objectives:

1. To highlight the meaningful partnership between patients, families, and researchers.
2. To showcase our experiences preparing for a research study to test the effectiveness of a transition app.

Description: Meaningful involvement of patients and families helps ensure that research has greater impact. Together in partnership, patients, families, and researchers have been working to develop and evaluate an e-health application to help youth with Brain-Based Disabilities (BBD) prepare for the transition from pediatric to adult health care. Since 2017, the research team and the Patient and Family Advisory Council (PFAC) have been meeting regularly. At the 2017 and 2018 CHILD-BRIGHT conferences, we shared our experiences in building our partnership and co-creating the MyREADY Transition™ BBD App. For the 2020 conference, we will showcase our ongoing collaboration to prepare for the READYorNot™ Brain-Based Disabilities Study Trial:

1. Participant Recruitment:
 - revising advertisements for brevity and clarity.
 - enhancing recruitment strategy to leverage social media connections.
 - scripting and recording novel testimonial videos for recruitment.
2. Data Collection:
 - pilot testing questionnaires for participants to:
 - i. resolve errors and offer insight about wording.
 - ii. improve flow and overall experience from a participant's perspective.
3. Engagement Plan:
 - Developing a plan to build a community of engagement by:
 - i. building capacity for engagement.
 - ii. creating engagement outreach with patients/families in recruitment regions.
 - iii. opening direct lines of communication between PFAC and recruitment sites.
4. Knowledge Translation (KT):
 - PFAC has influenced KT planning discussions, with guiding questions such as:
 - i. How can we be creative?
 - ii. What do we hope to change or influence with the project?
 - iii. How can outputs from this project help young people and their families?

Significance and Next Steps: We see the richness that our ongoing partnership brings to the project and we are planning ways to evaluate engagement impact from different perspectives. Our next steps include having check-in meetings with PFAC members. These will be guided by the “Start, Stop, and Continue” Exercise to identify future activities and by the Involvement Matrix to proactively discuss roles.