



# READYorNot™

## Brain-Based Disabilities Trial



### Report to Participants & Families: Study Results

March 2023

#### What is health care transition?

In Canada by the time youth with disabilities turn 18, they are usually expected to move from a family-centred children’s hospital or treatment centre to looking after their own health in adult health services. It is hoped that they will start taking charge of their own health care needs (for example, talking on their own with doctors and nurses, making appointments, taking medications). We call this health care transition.

The health care system has guidelines about the age of transfer to adult health care and the transition happens whether youth are ready or not. If the transition is not smooth, it can have a negative effect on a person’s health and quality of life. When we do not prepare youth to start taking charge of their health care, they might miss appointments or medications and their health may worsen. This can create concerns for youth, families, care providers and health care systems.

We aim to balance those concerns. As doctors and researchers, we look for ways to give youth and families the best health and health care transition experience possible.

#### What was the study about?

In this study, researchers, health care professionals, technology experts, youth, and families, including our Patient and Family Advisory Council (PFAC) members, all worked together on a digital application (App) called MyREADY Transition™ BBD App. The App is for young people who are 15, 16 or 17 years

old, and who have autism spectrum disorder, cerebral palsy, epilepsy, fetal alcohol spectrum disorder, or spina bifida. The App was created to help youth start to get ready for health care transition. It takes a step-by-step approach to helping youth build knowledge and skills to start taking charge of their own health.

We created this [research video series](#) to help explain some of the details about the study.

How does this RCT work?	Why did we make the App?	What can the App do for you?
Can anyone use the App?	What is this research about?	How are you put into groups?
What’s in it for you?	Why do you answer questionnaires?	<b>CLICK ON A BOX TO WATCH A SHORT VIDEO ON YOUTUBE</b>

#### Who took part in the study?

It was a Canadian study with participants in Alberta, Ontario, Quebec, and the Maritimes.

We aimed to enroll 264 participants (66 in each of the regions). We did our best and adapted the study during the COVID-19 pandemic. We were not able to find as many participants as planned. By the end of the study period, 52 youth and families took part in the study; 24 of these were randomly chosen to use the App. Of these, seven youth and five parents agreed to be interviewed about their experiences with the App.

## What did the study tell us?

This study was designed to learn whether there was a benefit to using the App, compared to not using it. With fewer people taking part in the study than hoped, we were not able to fully evaluate the App in the ways we had planned. Instead, we focus the study results below on what we learned from youth and families who used the App.

### What we learned from youth

Youth provided both positive and negative feedback. Of the 24 youth who were randomly chosen to use the App, one was not able to download the App onto their device at all. Some had problems with videos freezing or the App glitching or crashing. Most youth said it was easy to move through the features and tools in the App. They liked the cues in the App to help them make their way through the visits. The main recommendation was for future users to be able to skip or choose the order and timing of the content. When asked about what they needed to get ready for health care transition, youth were often not able to see a connection between what they needed and what the App had to offer.

*“When you get someone who's speaking [in a video] who has your diagnosis, it's like, yay. I don't know. I just felt kind of happy...it's just easier to process what they're saying when someone's speaking and it's not just text.”*

*“The videos were stuff that I either already knew or didn't care enough to know. Stuff that I felt like I didn't need to hear.”*

### What we learned from parents

Parents who reviewed the App content found the information useful and comprehensive. They recommended customization to offer a balance between required content and information youth could choose based on their personal questions and needs. Parents also talked about the difficulty for youth to apply what they learned in the App to their own lives.

### What we learned from care providers

Doctors and nurses could imagine working with youth who are using the App, to achieve the goals they have set for themselves (for example, asking questions and meeting a doctor on their own). This way, youth who are developing transition knowledge and skills could practice in real life situations.

## Key take-aways from this study

We wanted to learn if the App would help youth with health care transition skills like knowing about their health, knowing what questions to ask, and when to ask for help.

On average, youth in the study completed fewer than 1/3 of the visits in the App. Youth and parents recommended for the order and content in the App to be customized based on personal questions and needs. We did not have this information before running this research study. This is why research is so important: It gives us a chance to learn what is working and what can be improved for a study intervention like an App.

### Based on what we learned in this study, our team is considering other ways to organize and deliver the App content:

- ❖ Overall, youth, parents and care providers told us the information provided in the App was relevant and useful to prepare youth for health care transition.
- ❖ More choice and customization are recommended in terms of when and how youth can access content.
- ❖ Youth do not transition alone, so having collaborative discussions between youth, parents and health care providers is key.
- ❖ Parents and health care providers may be able to help coach and work with youth to better incorporate the App into care and to help apply the skills in real life situations.
- ❖ The App could be better optimized for mobile use (for example, fewer glitches).

Thank you for participating! We value the chance to learn from families like yours as you are preparing for health care transition.

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