TRANSITIONAL CARE FOR YOUTH WITH PHYSICAL DISABILITIES

TRANSITIONAL CARE ALUMNUS PARTICIPANT CONSENT FORM

Principal Investigator:
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You are being invited to participate in a research study conducted by Dr. Charles Pickard because you are an adult individual (18 years old to 30 years old) with chronic physical disability. We have outlined for you in this document the details of a local needs assessment being conducted by Dr. Pickard to evaluate the need for additional transitional care support in Kitchener-Waterloo, as well as to develop insight into the development of an effective transitional care program model for local youth individuals with physical disabilities. The potential risks and benefits associated with your participation are outlined below. Please take your time to review this consent form before making a decision on participation. There are no conflicts of interest to report.

What is the purpose of this study?

Children with chronic physical disabilities often face challenges maintaining healthcare access once they turn 18 years old and must transition from their childhood healthcare team to adult care. The purpose of this study is 3-fold:

1) Establish local statistics and demographics on youth individuals with physical disabilities in order to understand the extent of the population that would benefit from a transitional care program
2) Identify current unmet needs in the transition process through a survey completed by youth individuals and their caregivers
3) Build consensus on what features should be included in a modern transitional care program by performing structured interviews with youth individuals with disabilities, caregivers, providers, and transitional care researchers

We will use this information to gauge the current state of transitional care support in our local area and identify unmet needs that exist within the current approach to transitional care. This information will help us determine whether a local transitional support program should be implemented to address unmet needs identified by this study. These questions will be explored through participant surveys and structured interviews with individuals involved in transitional care at all levels from the individuals who are undergoing the transition of care to the healthcare providers.

What will my responsibilities be if I take part in this study?

If you agree to participate in this study, your involvement will consist of completing a survey enquiring about your healthcare experience and thoughts on transitioning to adult care as well as taking part in 1 interview lasting approximately 30 minutes to 60 minutes with a research associate. Depending on

provider availability, the interview will be offered in person, via telephone, or through short-answer written response.

Will I be paid to participate in this study?

Participants who complete an interview will be compensated with a $50.00 gift-card for their time.

What are the possible risks and discomforts and the possible benefits for me and/or society?

Participant risks for this study are minimal. Participant interview data will be anonymized and stored on private secure computers. Health information relating to pediatric participants will be limited to types of physical disability, types of healthcare services utilized, and opinions on improving healthcare support. If you agree to participate, you may decline to answer any question(s), and you may stop the interview at any time. Your decision to participate or not will not affect your relationship with your care providers.

How many people will be in this study?

We are anticipating interviews with up to 20 youth individuals with chronic physical disabilities along with one caregiver per youth participant, up to 20 local pediatricians, and up to 5 regional researchers with expertise in transitional care.

Can I decline to participate in this study?

You are under no obligation to participate with this study and you will be able to withdraw from this study at any time should you initially choose to participate.

What information will be kept private?

The information gathered during this study will be anonymized which means we will remove information that could be used to identify a participant. Study data will not be shared with party outside of our research team. Interviews will be digitally recorded and transcribed where potentially identifying data will be deleted following preliminary data analysis. All study data including interview recordings will be stored on a private password protected computer and any hardcopies of the study data will be securely stored in a locked office. Remaining anonymized study data will be destroyed one year after the conclusion of this study.

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the Hamilton Integrated Research Ethics Board (HiREB) may request our study research data.

We intend to publish results from this study in a peer-reviewed journal. If the results of this study are published, your name will not be used and no information that discloses your identity will be released or published.

Can participation in the study end early?

You may withdraw participation at any point during the study by contacting a member for the research team. Withdrawal from the study has no impact on the care you receive.

Do I need to sign a consent form?

Yes, we ask you to provide your signature below to indicate your understanding of this study's parameters and your willingness to participate in this study.

Will there be any costs?

Your participation will not involve any additional costs to you, or your health care insurer.

If I have any questions or problems, whom can I call?

If you have any questions about the research, now or at some point in the future, please contact the research associate at 1-519-783-0020 Ext 3085.

This study has been reviewed by Hamilton Integrated Research Ethics Board. If you have any questions regarding your rights as a research participant, you may contact the Office of the Chair of the Hamilton Integrated Research Ethics Board at 905-521-2100, ext. 42013.

Participants:

I have read the invitation to participants thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I will receive a signed copy of this consent form.

I agree to submitting personal demographic information and insights for the purposes of data analysis. No identifiable information will be retained. **I agree to participate in this study**.

Name (alumnus participant)	Signature	Date

Person obtaining consent:

I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study.

Name, Role in Study	Signature	Date

Sincerely,

Charles Pickard, MD CCFP
The Centre for Family Medicine Family Health Team