

Informed Consent Form

HEALTH AND PHYSICAL ACTIVITY AMONG CHILDREN WITH INTELLECTUAL DISABILITIES

York University

Primary Researchers: Rebecca Bassett-Gunter, York University, School of Kinesiology and Health Science, Stong College, Room 310, 4700 Keele St. Toronto, ON M3J 1P3; 416.736.2100 ext. 22072, rgunter@yorku.ca.

Background: This research project is focused on understanding the physical activity support behaviours of parents of a child(ren) with an intellectual disability. The following brief is intended to provide you with the necessary details prior to giving consent to participate in this study. Please read the following information carefully and feel free to ask any questions.

Purpose of the Research: To explore physical activity support behaviours of parents of a child(ren) with an intellectual disability.

What You Will Be Asked to Do in the Research:

Stage 1: Following an eligibility assessment, you will be randomly assigned to one of five groups and asked to complete a series of questionnaires. Firstly, a demographic questionnaire will be administered to provide the research team with information regarding participant characteristics, followed by an online questionnaire (Q1) exploring parental support behaviours towards physical activity. Together, these online questionnaires will take approximately 20 minutes to complete. Following your completion of Q1, you will be provided with some information about children with intellectual disabilities in the form of an e-newsletter. Immediately after reading the e-newsletter, you will be asked to complete a follow-up questionnaire (FQ1). The follow-up questionnaire will take approximately 10 minutes to complete.

Stage 2: Two weeks later, you will be contacted via email and asked to complete a second follow-up questionnaire (FQ2). The second follow-up questionnaire will take approximately 10 minutes to complete.

Stage 3: Finally, approximately two months later, you will be asked to complete a third follow-up questionnaire (FQ3). The third follow-up questionnaire will take approximately 10 minutes to complete.

Participants will receive a \$25 online gift card for their participation in this study. The honorarium will be distributed across the three stages of this study as follows;

Stage 1: \$15

Stage 2: \$5

Stage 3: \$5

Should the participant withdraw during any stage, they will still be eligible for the honoraria up to and including the stage in which they withdrew, but not for subsequent stages.

Risks and Discomforts: The researchers strive to ensure that the psychological and emotional well-being of parents and caregivers of children with intellectual disabilities are not adversely affected by their participation in this study. A document containing information to various organization and support resources is available upon request.

Benefits of the Research: No direct benefits are anticipated for the participants.

Voluntary Participation: Your participation in this study is completely voluntary. Your decision not to volunteer will not influence your relationship with York University either now, or in the future.

Withdrawal from the Study: You can stop participating in the study at any time, for any reason, if you should so decide. Your decision to stop participating, or refusal to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this

project. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

Confidentiality: All information you supply during the research will be held in confidence and your name, nor will the name of your child, appear in any report or publication of the research. Your data will be safely stored in a locked facility and / or on a password protected computer and only research staff will have access to this information. Data will be stored for the duration of the study and will subsequently be destroyed. Confidentiality will be provided to the fullest extent possible by law.

The researcher(s) acknowledge that the host of the online survey (e.g., Qualtrics, Survey Monkey etc.) may automatically collect participant data without their knowledge (i.e., IP addresses.) Although this information may be provided or made accessible to the researchers, it will not be used or saved without participant's consent on the researchers' system. Because this project employs e-based collection techniques, data may be subject to access by third parties as a result of various security legislation now in place in many countries and thus the confidentiality and privacy of data cannot be guaranteed during web-based transmission.

Questions About the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Rebecca Bassett-Gunter by telephone at 416.736.2100 ext. 22072 or by email (rgunter@yorku.ca). This research has been reviewed and approved by the Human Participants Review Sub-Committee of York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Senior Manager and Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

Legal Rights and Signatures:

I consent to participate in: **HEALTH AND PHYSICAL ACTIVITY AMONG CHILDREN WITH INTELLECTUAL DISABILITIES** by Dr. Rebecca Bassett-Gunter. I have understood the nature of this project and wish to participate. By clicking "I agree" below, I indicate my consent.

I AGREE

I DISAGREE

December 10, 2019

Dr. Rebecca Bassett-Gunter, PhD
School of Kinesiology and Health Science
York University
310 Stong College

Dear Dr. Bassett-Gunter,

The Canadian Disability Participation Project (CDPP) is pleased to support your research titled “Health and Physical Activity Among Children with Intellectual Disabilities”. I have thoroughly read the proposal and fully endorse its objectives.

The CDPP is an alliance of university, public, private and government sector partners working together to enhance community participation among Canadians with disabilities. We are pleased to leverage our networks and partnerships in order to support and facilitate participant recruitment. Using various avenues (e.g., social media, website, and distribute study postcards), the CDPP will connect with families of children with intellectual disability and invite them to participate in this research project. To respect the privacy and rights of the CDPP and its participants, information about the study will be distributed at our discretion. We intend to provide information regarding the study protocol, as well as contact information for the research team. Interested parents will be urged to contact the study team directly to discuss participation and inquire about any further details.

Participation of any parent will be completely voluntary and each parent will make an independent decision as to whether or not they would like to be involved. Parents will be reminded of their rights to participate or withdraw at any time. Participation (or lack thereof) in this study will not affect parents’ relationships with the CDPP or associated groups.

We look forward to actively supporting participant recruitment for this project. The CDPP is excited to support research which is taking steps towards effectively communicating the benefits of and strategies to enhance engagement in physical activity participation for children and youth with a disability.

Sincerely,



Kathleen A. Martin Ginis, PhD., O.M.C.
Chair & Principal Investigator, CDPP

kathleen_martin.ginis@ubc.ca



December 10, 2019

Dr. Rebecca Bassett-Gunter, PhD
School of Kinesiology and Health Science
York University
310 Stong College

Dear Dr. Bassett-Gunter,

Special Olympics Ontario is pleased to support your research titled "Health and Physical Activity Among Children with Intellectual Disabilities". We have thoroughly read and reviewed the proposal and fully endorse its objectives.

Special Olympics Ontario is dedicated to enriching the lives of people with intellectual disabilities through sport. We believe that the creation of meaningful, fully accessible and quality physical activity, health and wellness opportunities will allow individuals with intellectual disabilities to become included and involved members of their communities.

Special Olympics Ontario has previously supported this project by funding two Research Assistants through our summer research program. The Research Assistants worked to gather pertinent literature identifying the need to increase parent support for physical activity among children with an intellectual disability. At this stage in the project we are pleased to leverage our network of parents/caregivers and individuals in order to support and facilitate participant recruitment. Using various avenues (e.g., social media, website, and distribution of collateral materials such as study postcards), Special Olympics Ontario will connect with families of children with intellectual disability and invite them to participate in this research project. To respect the privacy and rights of Special Olympics Ontario and its participants, information about the study will be distributed at our discretion. We intend to provide information regarding the study protocol, as well as contact information for the research team. Interested parents will be urged to contact the study team directly to discuss participation and inquire about any further details.

Participation of any parent will be completely voluntary and each parent will make an independent decision as to whether or not they would like to be involved. Parents will be reminded of their rights to participate or withdraw at any time. Participation (or lack thereof) in this study will not affect parents' relationships with Special Olympics Ontario or our program partners. We look forward to actively supporting participant recruitment for this project.

Special Olympics Ontario is excited to support research which is taking steps towards effectively communicating the benefits of and strategies to enhance engagement in physical activity participation for children and youth with a disability.

Sincerely,

A handwritten signature in black ink, appearing to read "James Noronha", with a stylized flourish at the end.

James Noronha
Program Director

Special Olympics Ontario

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Created by the Joseph P. Kennedy Jr. Foundation. Authorized and accredited by Special Olympics, Inc for the benefit of persons with intellectual disabilities.