

Informed Consent Form
UNDERSTANDING PERSPECTIVES ON HEALTH BEHAVIOURS AMONG
PARENTS OF CHILDREN, YOUTH, AND YOUNG ADULTS WITH AN
INTELLECTUAL DISABILITY OR AUTISM
York University

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Background: This research project is focused on understanding the health behaviours of parents of children, youth, and young adults with an intellectual disability or autism. 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 perspectives on health behaviours among parents of children, youth, and young adults with an intellectual disability or autism.

What You Will Be Asked to Do in the Research:

Stage 1: Following an eligibility assessment, you will be asked to complete a series of questionnaires. Firstly, a demographic questionnaire will be administered to provide the research team with information about you, followed by an online questionnaire exploring parental support behaviours towards physical activity. Together, these online questionnaires will take approximately 10 minutes to complete. Next, you will be provided with some information in the form of a newsletter. Immediately after reading the newsletter, you will be asked to complete another questionnaire. This questionnaire will take approximately 10 minutes to complete.

Stage 2: Two weeks after completing Stage 1, you will be contacted via email and asked to complete a second questionnaire, which will take approximately 10 minutes to complete.

Stage 3: Finally, approximately two months after completing Stage 2, you will be asked to complete a third series of questionnaires, which will take approximately 15 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 you withdraw during any stage, you will still be eligible for the honoraria up to and including the stage in which you withdrew, but not for subsequent stages.

Risks and Discomforts: The researchers strive to ensure that the psychological and emotional well-being of parents, legal guardians, and primary caregivers of children, youth, and young adults with an intellectual disability or autism are not adversely affected by their participation in this study. A document containing information regarding various organizations 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 or any other group associated with this project 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. Your name and your child, youth, or young adult's name will not 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 researchers acknowledge that the host of the online questionnaire (SurveyMonkey) may automatically collect participant data without their knowledge (e.g., IP addresses). Although this information may be provided or made accessible to the researchers, it will not be used or saved without your consent. 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 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 **UNDERSTANDING PERSPECTIVES ON HEALTH BEHAVIOURS AMONG PARENTS OF CHILDREN, YOUTH, AND YOUNG ADULTS WITH AN INTELLECTUAL DISABILITY OR AUTISM** 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