

## Explanatory Statement

### **Title: Mothers of a child with a disability: Perspectives on health, healthy behaviours and family access to the community**

#### **Principal researchers:**

Associate Professor Helen Bourke-Taylor, Senior Lecturer, Department of Occupational Therapy, Monash University

Associate Professor Ted Brown, Senior Lecturer, Department of Occupational Therapy, Monash University

Miss Aislinn Lalor, Senior Lecturer, Department of Occupational Therapy, Monash University

Associate Professor Prue Morgan, Senior Lecturer, Department of Physiotherapy, Monash University

Mrs Elizabeth Knightbridge, Senior Lecturer, Department of Occupational Therapy, Monash University

Associate Professor Louise Farnworth, Senior Lecturer, Department of Occupational Therapy, Monash University

Professor Dinah Reddihough, Royal Children's Hospital, Flemington Road Parkville

Professor Jenny Ziviani, Childhood Disability, Children's Health Queensland Hospital and Health Service, University of Queensland

Ms Kahli Joyce, Research Affiliate, Department of Occupational Therapy, Monash University

#### **Your Consent**

You are invited to participate in the *Mothers of a child/young person with a disability: Perspectives on health, healthy behaviours and family access to the community* research study as you are a mother of a child over 5 years of age who has a disability or chronic medical condition. Please read this Explanatory Statement in full before making a decision to participate. The information sheet is yours to keep.

#### **The purpose of this research**

This project investigates relationships between subjective health, health behaviours, community engagement and work among Australian mothers of children with a disability/severe chronic medical condition. In particular, this study seeks to identify and quantify maternal and family inclusion and engagement in the community. Understanding mother's perspectives of their local environments, their health behaviours and how they pursue community-based health-promoting opportunities provides the first step in understanding how environments may be altered to enhance you and your families' engagement in healthy community based activities.

Further, this study provides an important step in the development of two new ways to measure just how accessible, inclusive and engaging community facilities are for families like yours.

#### **Possible benefits**

Participation in this study may not immediately benefit your own personal health. However, your participation will assist us in determining how accessible Victorian environments are to families of children with a disability, as well as draw correlations between environmental accessibility, engagement in healthy lifestyle choices, and mothers' health and wellbeing. Long term, this information serves as a much-needed stepping stone to designing and creating universally accessible environments to promote mothers' and families' engagement in health-promoting recreational activities.

### **What does the research involve?**

This research involves completing a single online questionnaire in your own time via the URL link provided [https://monash.az1.qualtrics.com/jfe/form/SV\\_0JtDWbcfIO1T5EV](https://monash.az1.qualtrics.com/jfe/form/SV_0JtDWbcfIO1T5EV). The questionnaire will ask you about your physical and mental health and wellbeing, lifestyle habits, engagement in health-promoting activities, and satisfaction with local environments and facilities.

Participation is voluntary and anonymous. If you agree to participate, you will need to complete and send back the initial questionnaire and the consent form in the reply paid envelope provided. If you decide you are not interested in participating after you read this explanatory statement, or after talking with the researchers, then your participation will then end.

### **How much time will the research take?**

It will take you about 30 minutes to complete the online survey.

### **Inconvenience/discomfort**

Reflecting on your health, how you feel, your role as a mother to your child with a disability, or on other areas of your life may be upsetting. You may consider some of the questions in the questionnaires personal or intrusive and you do not have to answer all questions if you do not wish to do so. If you feel unsettled or have further questions about your health, we advise that you contact your general practitioner immediately. Please contact one of the following services if you need prompt assistance: Lifeline (ph. 13 11 14), or Association for Children with a Disability - Parent Support Worker (ph. 9818 2000 or 1800 654 013 or email [mail@acd.org.au](mailto:mail@acd.org.au)). Please consider investigating local counselling services by entering your postcode in the Carer Gateway, see <https://www.carergateway.gov.au/>.

### **Payment**

There is no payment for participation in this research.

### **Can I withdraw from the research?**

Being in this study is voluntary and you are under no obligation to consent to participation. You may withdraw at any time up until submission of the survey by exiting the survey window and/or closing your web browser and this is entirely up to you.

### **Confidentiality**

Anonymous data will be collected via your completion of the online survey hosted by Qualtrics Survey Software. Qualtrics is a secure web-based platform that uses data encryption and transport layer security to protect your information at all times.

By selecting the consent box on a page of the online survey, you agree to participate.

### **Storage of data**

Data collected will be stored in accordance with Monash University regulations and Victorian privacy laws and kept in secure electronic storage for 5 years. A report of the study may be submitted for publication, but individual participants will not be identifiable in any publication or on the website.

### Use of data for other purposes

The data collected in this research is anonymous. In the future, it is possible that this data may be used for other research purposes. Because it is anonymous data, nobody can be named or identified in any way. For example, future research may investigate the situation of unwell mothers, older or younger women or men. This research would serve as comparative data. By selecting the box on the the Consent Form you agree to your data to be used in this manner.

### Results

If you would like to be informed of the aggregate research finding, please contact Associate Professor Helen Bourke-Taylor on 9904 4471 or [helen.bourke-taylor@monash.edu](mailto:helen.bourke-taylor@monash.edu). Please note that your personal results will not be available as all data will be de-identified. The results of the study will be presented as group data.

### Is the research approved?

The ethical aspects of this research have been approved by the Human Research Ethics Committee of Monash University (Project 10958). This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National; Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

If you would like to contact the researchers about any aspect of this study, please contact the Chief Investigator:	If you have a complaint concerning the manner in which this research <b>project 10958</b> is being conducted, please contact:
Associate Professor Helen Bourke-Taylor PhD Senior Lecturer, Occupational Therapy Program School of Primary Health Care Faculty of Medicine, Nursing and Health Sciences Monash University - Peninsula Campus PO Box 527, Frankston, Victoria, 3199 Phone 039 904 4171	<b>Executive Officer</b> <b>Monash University Human Research Ethics Committee (MUHREC)</b> <b>Building 3e Room 111</b> <b>Research Office</b> <b>Monash University VIC 3800</b>  <b>Tel: +61 3 9905 2052 Fax: +61 3 9905 3831</b> <b>Email: <a href="mailto:muhrec@monash.edu">muhrec@monash.edu</a></b>

Thank you.



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