

Explanatory Statement

Title: Fathering a child or young person with a disability: What helps, hinders and supports fathers in their important role in the family?

Principal researchers:

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Ms Kahli Joyce, Occupational Therapist, Research Affiliate, Monash University

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Your Consent

You are invited to participate in this research if you are the father of a child or young person with a disability. 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

The research aims to explore your experience fathering a child with a disability. The research also aims to gain your perspective of ways that the service system or others might better support fathers and families like yours. Fathers are important members of families. Father's health and engagement is paramount to their own quality of life, as well as their families. However, little is known about what fathers both need and want from the service system surrounding their child/young person with a disability and family and the community in order to feel satisfied and included in their child's interaction with services and their life. Further, this research aims to gain an understanding of fathers' roles and activities within the family, with their partner and children. The findings of this research will be used to improve the support offered to fathers and also understanding of their role.

Possible benefits

Participation in this study may not immediately benefit your own personal health or well-being. However, your participation will assist us in developing more tailored services for fathers of children with a disability or medical condition, and improved understanding for health professionals about the health and life situation of fathers, and ultimately improve services for families with a child or young person with a disability.

What does the research involve?

This research involves completing a single online questionnaire in your own time via https://monash.az1.qualtrics.com/jfe/form/SV_erkpW0m0BO45gKp. The questionnaire will ask you about your role as a father, your opinions about aspects of your child's care, your physical and mental health and wellbeing, lifestyle habits, engagement in health-promoting activities, paid work and satisfaction and involvement in local environments and facilities. The final question will ask whether

you would like to participate in a brief interview with a member of the research team to further discuss your experiences and needs as a father of a child with a disability. Participation in the interview is completely voluntary. If you agree, a member of the research team will contact you via email to setup a suitable time. If you would prefer not to participate in an interview, your participation in this research study will end.

Participation is voluntary and anonymous. If you agree to participate, you will need to agree to the consent statement, complete and submit the questionnaire online. If you decide you are not interested in participating after you read this explanatory statement, then your participation will 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 father to your child with a disability, or on other areas of your life may be upsetting for some men. You may consider some of the questions in the online survey to be personal 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). 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 the first page of the online survey, you agree to complete the survey as an anonymous participant.

The final survey question will ask whether you would like to participate in a brief interview with a member of the research team to further discuss your experiences and needs as a father of a child with a disability. If you agree, your survey data will be linked to your interview, meaning your responses to the survey are no longer anonymous. Your data will be kept in secure storage, accessible only to the research team named on this document. Further, all data will be analysed and presented in aggregate form; in any publication, information will be provided in such a way that you cannot be identified.

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 fathers, older or younger men or women. 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. Please note that your personal results will not be available and cannot be extracted from the whole group. 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 number 10957](#)). 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 project 10957 is being conducted, please contact:
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Thank you,



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