

Disability, Home and Family in a Multicultural Context

He Pānui Pāroko

Questionnaire Participant Information Sheet

Tēnā Koe,

You are invited to participate in a questionnaire about disabled people's experiences of home and family in Aotearoa New Zealand.

He aha te kaupapa o taua nei rakahau?

What is this research about?

Aotearoa New Zealand is home to many diverse peoples, each with a unique understanding of 'home' and 'family'.

But the way we think about home and family has evolved over time, with families taking on many shapes and forms. For example:

- blended families;
- single-parent families;
- families headed by unmarried partners;
- rainbow families;
- multigenerational households;
- adoptive, foster and whangai families;
- and more.

For disabled people, our experience of home and family is not only impacted by culture, but also our experiences of disability, health and wellbeing. This includes the intimate role of support workers in our homes, and their engagement with us and our families.

Article 23 of the United Nations Convention on the Rights of Persons with Disabilities (Respect for Home and the Family) tells us that disabled people have a right to a home and family. But what does this mean in the context of modern-day Aotearoa New Zealand?

In this study we want to explore this question by asking disabled people and their family/whānau/aiga what they think about Article 23, and what respecting the right to home and family means to them.

Ko wai mātou?

Who is doing this research?

The research is being carried out by a research team from the Donald Beasley Institute (DBI). The DBI is a disability research institute that is based in Ōtepoti, Dunedin.

Researchers working on this study include Dr Brigit Mirfin-Veitch (Kaiwhakahaere/Director), Dr Robbie Francis Watene (Kairakāhau Matua/Senior Researcher), Dr Solmaz Nazari (Kairakāhau /Researcher) and Umi Asaka (Paewai Rakāhau/Junior Research Fellow), as well as other researchers from the DBI. Robbie, Solmaz and Umi are all disabled, and have experience in disability rights research.

Mā wai e whakauru i taua nei rakāhau?

Who can participate in this research?

Anyone who is over the age of 18, identifies as disabled or a family member, whānau, aiga, or close supporter of a disabled person, and can provide free and informed consent, can take part in the questionnaire.

How can I take part in the questionnaire and what will I do?

If you are interested in taking part in the questionnaire, please follow the link:

<http://surl.li/cjhqe>

If you would like to answer the questionnaire in print, by email, over the phone, or by Zoom, please contact the research team.

Dr Solmaz Nazari (Kairangahau)

Waea / Free phone: 0800 878 839

Īmēra / Email: Snazari@donaldbeasley.org.nz

www.donaldbeasley.org.nz

Wāhi Mahi / Postal Address: Suite 4, Level 2

248 Cumberland Street

Dunedin 9016, New Zealand

In the questionnaire you will be asked questions about:

- Your family, whānau and aiga
- Cultural perspectives on family, whānau and aiga
- The right to home and family

You will also be asked basic demographic information (for example, age, ethnicity, gender and disability type).

The questionnaire will take approximately 30 - 60 minutes to complete, depending on how much you would like to share with us.

What will happen with the information I tell you?

This research will take part under the korowai of our guiding values, which are:

- Whakamana (Ethical)
- Whakarakatira (Respectful)

- Whakawhanaukatakā (Relational)

We will keep your information private. The research team will not talk to any other person about you, without your consent, unless the safety of you or someone else is at risk and we are legally required to do so.

The only time we might share what you have told us with someone else is if you tell us that you are being abused, or abusing someone else. But we will talk with you before we do this.

You will be able to review and edit your questionnaire responses up to two weeks after submission, upon request. While we will use some of the things you tell us in the Project Report and other published articles, we will make sure that nothing will be used that could personally identify you.

There may be a delay between taking part in the questionnaire, and receiving the final Project Report.

Who will have access to my information, details and questionnaire responses?

The DBI research team and transcribers will be the only people who have access to the details and information you share. We will use a code system to help make sure no one can identify you or your responses.

What will happen to the information and details I share in this research?

Everything you share with us will be kept securely at the Donald Beasley Institute for 10 years. After 10 years it will be destroyed.

What happens if I don't want to take part in the questionnaire?

Nothing. If you don't want to take part it is OK. No one can tell you that you have to take part in the questionnaire.

If you don't want to take part, but still want to know about future studies, please register your interest with DBI by phone or by email.

What happens if I decide to take part in the questionnaire but then I change my mind?

Nothing. It is ok to decide to take part and then change your mind. You can withdraw consent and decide to stop participating at any time and nothing will happen to you. If you withdraw, it is your choice whether we can use the information you have told us in the questionnaire.

What if I get hurt?

It is unlikely that you will be hurt or injured during this study. If you feel any emotional distress related to the study, we will talk with you about how and where to access support.

Who do I contact for more information?

For more information you can contact the DBI Research Team on admin@donaldbeasley.org.nz or 0800 878 839. The call won't cost you any money.

Who can I contact for Māori research support?

If you would like to speak directly with the Kairākahau Māori Research Associate for the Donald Beasley Institute, Dr Kelly Tikao, please contact our office:

admin@donaldbeasley.org.nz

Free phone: 0800 878 839

Who can I contact if I need independent advice about taking part?

If you want to talk to someone who isn't involved with the research, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@advocacy.org.nz
Website: <https://www.advocacy.org.nz/>

Who do I contact if I have any concerns about the ethics of this study?

This research has been approved by the Northern B Health and Disability Ethics Committee (2022 FULL 12434). This means that a special group of people have made sure that the research is safe and that we will work with people in a respectful way.

Contact details for the ethics Committee are:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz