



Disability, Home and Family in a Multicultural Context

Participant Information Sheet

Kia ora,

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

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 family and home 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 home



and family. But what does this mean in the context of modern-day Aotearoa New Zealand?

In this study we want to talk to 12 disabled people from different family arrangements about their right to home and family, and what respecting this right means in modern-day Aotearoa New Zealand.

Who will be doing the 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, Dr Robbie Francis Watene, Dr Solmaz Nazari and Umi Asaka, as well as other researchers from the DBI. Robbie, Solmaz and Umi are all disabled, and have experience in disability rights research.

Who can participate in an interview?

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 an interview.

What will I have to do if I am chosen to take part?

If you are chosen to take part in this research you will be interviewed once, at a time and place of your choosing (Covid-19 alert level dependent). This could be in your home, or another place where you can talk in private. All of our research team are vaccinated, but we can also arrange for the interviews to be conducted via Zoom or phone if needed or preferred.



The DBI will arrange any access supports you might need to participate (for example, a New Zealand Sign Language Interpreter or accessible venue). The interviews will be recorded, but you can ask to have the recorder turned off whenever you want to. The researcher might write down some notes during the interviews and after they end.

In the interview we will ask you some questions about:

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

The interviews will take up to 1.5 hours each (inclusive of whakawhanaungatanga and consent process). A \$50.00 voucher will be given to each participant as koha - an acknowledgement of the time and expert knowledge you have given to the research.

What will happen with the information I tell you?

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.

The interviews will be recorded and transcribed, and you will be able to review and edit your transcript if you want to. While we will use some of the things you tell us in a 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 this research, and receiving the final project report.

How will cultural customs be included and respected throughout the research?

All participants will be asked if there are any cultural customs or traditions they would like recognised or implemented throughout the research process. For example, Māori participants may feel more comfortable participating in the interview with researchers who are familiar with tikanga Māori. At the participant's request karakia timatanga (opening blessing) and a mihi (greeting process) can take place before the interview and karakia mūtunga (closing blessing) at the end.

For meetings at the participant's home the researchers will ask what protocols to follow.

All participants can have a support person/people with them during the interview or focus group if they wish. However, any responses contributed by non-consenting support people will not be collected as data.

What do I do if I want to take part?

If you want to take part in an interview, please fill out the Participant Interest Form on our website. You can also print out a Word Doc Participant Interest Form, fill it out and post it to us at the DBI, email it to us, or you can contact the DBI research team and we will help you fill it out. If you would like to register your interest in New Zealand Sign Language, you can also email us a video of your responses. It is ok to ask a friend, family member or a support person to help you fill out the form if you want to. Please send your completed Participant Interest Forms to:

Robbie Francis Watene
The Donald Beasley Institute



www.donaldbeasley.org.nz

Free phone: 0800 878 839

Email: rfrancis@donaldbeasley.org.nz

Postal Address:

Suite 4, Level 2
248 Cumberland Street
Dunedin 9016, New Zealand

After we have received your Participant Interest Form someone from the research team will contact you and talk to you about the research again, just to make sure you really want to take part.

If a lot of people want to take part in this part of the research we may not be able to include everyone. This is not because we don't think your experience is important. Even if we can't talk with you in person, you can share your views using the questionnaire on our website and we will keep you informed about the progress of the research.

Who will have access to my information, details and interview recordings and notes?

The 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 be part of the research?**

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

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

What happens if I decide to take part in the research 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 the researcher uses the information you have told them up until that time.

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 health support?

If you would like to speak directly with the Kairangahau Māori Research Associate for the DBI, 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. 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