



**My Experiences, My Rights: Health and Wellbeing
Phase Two Monitoring Interviews - Participant Information Sheet**

You are invited to register your interest in participating in a study about disabled people's experiences of health and wellbeing in Aotearoa New Zealand. 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 Dunedin.

What is this research about?

In Aotearoa New Zealand, essential healthcare is provided free for those who qualify through the public health system.

But sometimes disabled people receive inadequate health and wellbeing treatment, care, and services. Sometimes they miss out altogether.

The United Nations Convention on the Rights of Persons with Disabilities is an international agreement.

It sets out what the Government of New Zealand must do to make sure disabled people have the same rights as everybody else.

This includes a disabled person's right to a high standard of health, without discrimination on the basis of disability (Article 25).

It is important to understand if, and how well, this is happening.



Earlier in 2020, we asked more than 100 disabled people, family/whānau, and close supporters of disabled people, about what health and wellbeing rights violations and issues they wanted us to monitor.

Now, we want to interview 100 more disabled people, family/whānau and close supporters, about their disability, health and wellbeing experiences.

These are called ‘monitoring interviews’.

We want to know what disabled people think and feel about the health and wellbeing treatment, care, and services they receive, and what types of treatment, care, and services they would like to receive in the future.

At the end of the research we will be able to give the Government of New Zealand and the United Nations some good information about disabled people’s current health and wellbeing experiences, and suggestions on how to meet the health and wellbeing needs of disabled people in the future.

Who will be doing the research?

Researchers working on this study are Umi Asaka, Dr Robbie Francis Watene and Dr Brigit Mirfin-Veitch from the DBI. We have all worked with disabled people in research projects for a long time, and Umi and Robbie are disabled too. The interviews will be conducted by ‘Research Monitors’. Research Monitors are disabled people trained by the DBI in monitoring research.



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

We are looking for 100 disabled New Zealanders and family/whānau or close support people from different backgrounds, regions, and with different disabilities to be interviewed.

If you are chosen to take part in this research you will be interviewed at least once by one or two Research Monitors by Zoom, or, face-to-face (dependant on Covid-19 restrictions). Some people may choose to do their interview with other people. This is called a focus group. A focus group is a small group of people who share a common characteristic, such as ethnicity, gender, or type of disability. The focus groups will meet together with the Research Monitors, and discuss the interview questions as a group.

The DBI will arrange any access supports you might need to participate (for example, a New Zealand Sign Language Interpreter or accessible venue).

In the interview we will ask you some questions about your personal experiences with the following:

- Access to the public health system;
- Access to health and wellbeing information;
- Care, treatment and services;
- Affordability;
- Policies and systems that impact your health and wellbeing;
- Covid-19 health and wellbeing;
- Anything else you wish to share about your right to a high standard of health.



The interviews will take about 1.5 hours. A \$50.00 voucher will be given to each participant as koha - an acknowledgement of the time and expert knowledge contributed to the monitoring research.

What will happen with the information I tell you?

We will keep your information private. The interviews will be audio or video recorded and transcribed, and you will be able to review and edit your transcript in plain written English if you want to. 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 this research, and receiving the final Project Report. It is important to note that the final Project Report might be used by Disabled People's Organisations, community health and disability support services, the Government of New Zealand and the United Nations to help them think about and to change the way they support disabled people access adequate health and wellbeing services.

If we are worried about your health or safety we will talk with you. 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.

What else will happen?

Because of Covid-19, it is likely that the interview will take place online using Zoom. In some circumstances we may be able to interview you face-to-face in a place you feel comfortable in. This could be in your home, or another place where you can talk in private. Focus groups will also take place on Zoom, and in some circumstances



face-to-face in accessible venues. If the focus group is being held in person, the DBI will arrange transport to and from the venue.

The interviews and focus groups will be audio or video recorded, but you can ask to have the recorder turned off whenever you want to.

The Research Monitors might write down some notes during the interviews and focus groups and after they end.

After the interview or focus group, the DBI Research Team may contact you again to ask if you would be willing to take part in a more detailed exploration of health and wellbeing issues.

Who can be in this research?

You can participate in this research if you are:

- Over the age of 18;
- Can provide free and informed consent;
- Identify as disabled, OR are a;
- Family/whānau member or close supporter of someone with multiple and complex disabilities who is unable to participate in the interview themselves.

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 research participants may feel more comfortable participating in the interview with a Research Monitor/s who are familiar with tikanga Māori. We will do our best to ensure



participants are matched with their preferred Monitor/s. At the participant's request karakia (blessing) and a mihi (greeting process) can take place before the interview or focus group and karakia mūtunga (closing blessing) at the end.

For meetings at the participant's home the Research Monitors 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-participating support people will not be collected as data.

What do I do if I want to take part?

If you are interested in taking part in a monitoring interview and would like to know more, please contact the Research Team at the Donald Beasley Institute by **5pm on Friday 30th October 2020**. We will send you more information so you can decide if you want to register your interest or not. We can help you fill out the Participant Interest Form.

If you are able to fill out the Participant Interest Form yourself please do so by answering the questions in the survey on our website or by filling out the attached Word Doc and emailing it back to us. You can also print the Word Doc, fill it out and post it to us at the DBI. 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.

Umi Asaka (Research Assistant)



The Donald Beasley Institute

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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 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 we will keep you informed about the progress of the research, and let you know how to access the final report when it is complete.

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

The DBI Research Team, Research Monitors, 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 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.

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 do I contact if I have any concerns about my safety?

This research has been approved by the Northern B Health and Disability Ethics Committee. This means that a group of experts 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

**Who can I contact for Māori health support?**

If you would like to speak directly with the Kairangahau Māori Research Associate for the Donald Beasley Institute, 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/>