**My Experiences, My Rights: Supports and Services**

**Strand Three - Questionnaire**

**Participant Information Sheet**

Tēnā Koe,

He tono tēnei ki a koe ki te hono mai ki tēnei kaupapa; he rakahau e pā ana ki kā rōpū tautoko i te huka whaikaha me kā wheako hoki o aua tākata whaikaha huri noa i Aotearoa.

You are invited to participate in a questionnaire about disabled people’s experiences of disability supports and services 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 Ōtepoti Dunedin.

**He aha te kaupapa o taua nei rakahau?**

**What is this research about?**

In Aotearoa New Zealand, the Government provides disabled people with supports and services that ensure their human rights can be realised in a full and meaningful way. For example, the right to health, education and housing.

Historically, disability supports and services have been provided by either the Ministry of Health (MoH) or Accident Compensation Corporation (ACC). The Ministry of Education, Ministry of Social Development, and Te Whatu Ora (formerly District Health Boards, DHBs) also provide some services. However, under this system, disabled people haven’t always received the supports and services they have wanted or needed. And sometimes they have missed out altogether.

In July 2022, Whaikaha - Ministry of Disabled People was established. One of the first tasks of Whaikaha is to roll out a new disability support system called Enabling Good Lives (EGL). These changes are still in their early stages.

This research project aims to monitor disabled people’s access to supports and services during these big changes. In this part of the research we want disabled people with a range of different support and service experiences, as well as family, whānau, aiga and close supporters **to answer a questionnaire.**

This project is part of the Disabled Person-Led Monitoring of United Nations Convention on the Rights of Persons with Disabilities in Aotearoa New Zealand. The UNCRPD sets out what the New Zealand Government must do to make sure disabled people have the same rights as everybody else. This includes a disabled person’s right to supports and services. It is important to understand if, and how well, this is happening.

We want to know what disabled people think and feel about existing supports and services, changes to the disability support system and Whaikaha - Ministry of Disabled People, and how these changes are meeting disabled people’s rights under the UNCRPD.

At the end of the research we will be able to give the New Zealand Government and the United Nations some good information about disabled people’s access to supports and services.

**Ko wai mātou?**

**Who will be doing the research?**

Researchers working on this study will be:

* Dr Brigit Mirfin-Veitch (Kaiwhakahaere/Director)
* Dr Robbie Francis Watene (Kairakahau Matua/Senior Researcher)
* Umi Asaka (Paewai Rakahau/Junior Research Fellow)
* Eden Tuisaula (Kairuruku/Research Assistant)
* Aroha Mules (Kairuruku/Research Assistant)
* Jacinta Tevaga (Kairuruku/Research Assistant)
* Wally Noble (Kairuruku/Research Assistant)
* Monica Leach (Kairuruku/Research Assistant)

We have all worked with disabled people in research projects for a long time, and Robbie, Umi, Eden, Aroha, Jacinta, Wally and Monica are disabled too.

**Mā wai e whakauru i taua nei rakahau?**

**Who can participate in the questionnaire?**

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

Family members and close supporters of people with multiple and complex disabilities are invited to contribute their own views and experiences in relation to the support and services experiences of the disabled person they support.

In other parts of the research we will be conducting one-on-one interviews and focus groups (please go to our website for more information).

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

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

<https://corexmss43gf6x5cw7qm.qualtrics.com/jfe/form/SV_ePppck9LBV21zNA>

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

Umi Asaka (Paewai Rakahau/Junior Research Fellow)

Free phone: 0800 878 839

Email: uasaka@donaldbeasley.org.nz

admin@donaldbeasley.org.nz

Website: www.donaldbeasley.org.nz

Postal Address:

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

In the questionnaire you will be asked some questions about your experiences with:

* Supports and services over the past 5 years;
* Whaikaha - Ministry of Disabled People, Enabling Good Lives, ACC and other support pathways;
* The transition from the former Health and Disability Support System to Whaikaha and Enabling Good Lives;
* What good support looks like for you and what you think needs to change for this to happen.

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.

**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.

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. 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 New Zealand Government and the United Nations to help them think about and to change the way they deliver supports and services.

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

The DBI research team 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, you can contact us 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 with the Kairangahau 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. 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