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

**He Pānui Pāroko**

**Focus Group 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 hauā me kā wheako hoki o aua tākata hauā huri noa i Aotearoa.**

You are invited to register your interest in participating in a study 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 based in Ōtepoti Dunedin.

**Ko wai mātou? Who is doing this 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/Deaf too.

**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 met 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 (MoE), Ministry of Social Development (MSD), and 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 this research we want to talk to disabled people with a range of different support and service experiences, as well as family, whānau and close supporters.

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 disability supports and services.

**Mā wai e whakauru i taua nei rakahau? Who can participate in this research?**

To take part in this part of the research (focus groups) we are looking for people who are over the age of 18, can provide informed consent, and who have different experiences relating to supports and services. Some examples of different focus groups are:

* ACC clients
* Individualised Funding (IF) clients
* People who participated in the Enabling Good Lives pilots
* Home and Community Support Services clients
* People whose funding/services/supports is provided by District Health Boards
* People who have no access to supports and services

We will also conduct focus groups with specific groups of people who are known to experience challenges in accessing services and supports. For example:

* Māori
* Pasefika
* Women
* Migrants and refugees
* LGBTTQIA+
* People living in group homes / People with learning disabilities
* People with psychosocial disabilities (Mental Health)
* Family, whānau, aiga and supporters of people with multiple and complex disabilities[[1]](#footnote-1)
* People whose funding/services/supports is provided by the Ministry of Education / Parents of disabled children[[2]](#footnote-2)
* D/deaf
* Rural

The reason we are conducting focus groups with these groups is so we can investigate their support and service experiences both before the national roll out of Enabling Good Lives, and during/after the national roll out.

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

**What will I do if I take part in this research?**

If you do take part in this part of the research you will be asked to participate in two focus groups. One at the beginning of 2023, and one towards the end of 2023. The focus groups will either take place via Zoom or in person.

The DBI will arrange any access supports you might need to participate (for example, transport, New Zealand Sign Language Interpreters, etc.). The focus groups will be 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 focus groups and after they end.

In the focus groups we will ask you some questions about your personal experiences with:

* The delivery of services, care and treatment, including support you need but have not had access to;
* The delivery of support during COVID-19;
* The delivery of information regarding the new Ministry, Enabling Good Lives and/or ACC (and other support pathways);
* Consultation regarding the new Ministry, Enabling Good Lives and/or ACC (and other support pathways);
* The transition from the current Health and Disability Support System to Enabling Good Lives;
* Funding;
* Policies and systems that impact the rights of disabled New Zealanders to live a ‘good life’ where their human rights are met in a meaningful and full way through supports and services.

The focus groups will take about 2 hours each. A $40.00 voucher will be given to each participant per focus group - an acknowledgement of the time and expert knowledge you have given to the monitoring research.

**What will happen with the information I tell you?**

This research will take part under Kā Matāpono (DBI Research Values), which are:

* Whakatinana – Honouring Te Tiriti o Waitangi through our practice
* Whakarakatira – Respectful
* Whakawhanaukataka – Relational
* Whakamana – Ethical
* Whakawhirinaki – Accountable
* Whakakotahi – Inclusive
* Whānau - Through uplifting whānau our journey will be one of prosperity

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 monitors will take every precaution to maintain confidentiality of the data. However, the nature of focus groups means we can’t guarantee confidentiality. Monitors will remind focus group participants to respect the privacy of other participants and not repeat what is shared in the focus groups to others.

The focus groups will be recorded and transcribed. 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 New Zealand Government and the United Nations to help them think about and to change the way they deliver supports and services.

Any information you give will be used for this research only and will not be used for any other purpose.

**How will cultural customs be included and respected throughout the focus group?**

During the focus groups 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, at the participant’s request karakia timatanga (opening blessing) and a mihimihi (greeting process) can take place before the hui and karakia mūtunga (closing blessing) at the end of the hui.

All participants can have a support person/people with them during the 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 in the focus group?**

If you want to take part in a focus group, please fill out the Participant Interest Form on our website. You can also download and 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 record a video using SeeFlow NZSL Direct (<https://seeflow.co.nz/direct>). SeeFlow will translate the video and send it to us.

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:

Umi Asaka (Paewai Rakahau/Junior Research Fellow)

**Waea** / Free phone: 0800 878 839

**Īmēra** / Email: uasaka@donaldbeasley.org.nz

www.donaldbeasley.org.nz

**Wāhi Mahi** / Postal Address: Suite 4, Level 2

 248 Cumberland Street

 Dunedin 9016, New Zealand

After we have received your Focus Group Participant Interest Form someone from the research team will contact you and talk to you about the focus group again, just to make sure you really want to take part. If you still want to participate, the research team will help you fill out a Consent Form.

If a lot of people want to take part in the focus group consultation 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 focus group recordings and notes?**

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 be part of the consultation?**

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

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 a focus group 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 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 research support?**

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

**Īmēra / email:** admin@donaldbeasley.org.nz

**Waea / 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

1. Family members and close supporters of people with multiple and complex disabilities will be invited to contribute their own views and experiences in relation to the support and services experiences of the disabled person they support. [↑](#footnote-ref-1)
2. As above [↑](#footnote-ref-2)