**Ka Whakawhanake he Ara Pūrua hei Kātoitoi i te Mahi Tūkino ki ō Tātou Wāhine Whaikaha**

**Developing a Twin Track Response to Family and Sexual Violence Against Wāhine Whaikaha, D/deaf and Disabled Women Project**

**He Pānui Pāroko**

**Disabled Women Strand - Participant Information Sheet**

Tēnā Koe,

He tono tēnei ki a koe ki te hono mai ki tēnei kaupapa tino whakahirahira; he rakahau ka whakawhanake he ara pūrua hei kātoitoi i te mahi tūkino ki ō tātou wāhine whaikaha.

You are invited to register your interest in research about developing a twin track response to family and sexual violence experienced by wāhine whaikaha, D/deaf and disabled women.

This Participant Information Sheet is to help you decide if you want to register your interest or not.

**Ko wai mātou? Who is doing this research?**

A group of disability researchers from around Aotearoa New Zealand are working on this research. Some of the researchers identify as disabled, and others have worked with disabled people in research for many years.

* Assoc. Prof. Brigit Mirfin-Veitch (Kaiwhakahaere/Director, Donald Beasley Institute)
* Assoc. Prof. Patsie Frawley (Ahoraki Tūhono/Associate Professor, University of Waikato)
* Dr Kelly Tikao (Kairakahau Māori/Senior Māori Researcher, Donald Beasley Institute)
* Dr Debbie Hager (Pūkeka/Lecturer, University of Auckland)
* Dr Robbie Francis Watene (Kairakahau Matua/Senior Researcher, Donald Beasley Institute)
* Umi Asaka (Paewai Rakahau/Junior Research Fellow, Donald Beasley Institute)
* Eden Tuisaula (Kairuruku/Research Assistant, Donald Beasley Institute)
* Aroha Mules (Kairuruku/Research Assistant, Donald Beasley Institute)

This research is funded by the Health Research Council and will be hosted by the Donald Beasley Institute, an independent disability research institute that is based in Ōtepoti Dunedin.

**He aha te kaupapa o taua nei rakahau? What is this research about?**

*Nā tō rourou, nā taku rourou, ka ora ai tō tātou whānau*

*This whakataukī encapsulates the notion that while working in isolation might result in survival, working together as a whānau can take us beyond survival and onto prosperity.*

Wāhine whaikaha, D/deaf and disabled women experience high rates of family and sexual violence. However, little is known about mainstream or specialist services that are able to respond to their specific needs.

Disabled people have told the government they want a disability rights-based approach to family and sexual violence prevention and support services. This includes a twin track approach. A twin track approach ensures mainstream prevention and support services are inclusive of, and accessible to, disabled people. It also recognises the need for specialised prevention and support services that are specific to disabled people, including disabled children and the whānau of disabled people.

This research responds to this call by asking wāhine whaikaha, D/deaf and disabled women, as well as people providing services, what is needed to make family and sexual violence prevention and support services accessible, and what a twin track approach needs to include.

**He aha ai ka rakahau i taua nei kaupapa? Why is this research important?**

*Mā te rongo, ka mōhio, Mā te mōhio, ka mārama, Mā te mārama, ka mātau, Mā te mātau, ka ora.*

*From listening comes knowledge, From knowledge comes understanding, From understanding comes wisdom, From wisdom comes well-being.*

At the heart of the disability rights movement is the mantra ‘nothing about us, without us’. It is important that a twin track strategy for family and sexual violence prevention and response is informed and led by wāhine whaikaha who have experienced family and sexual violence themselves. It is also important to talk to prevention and support services about their current approaches to supporting wāhine whaikaha, D/deaf and disabled women, and what new approaches might be needed.

**Me pēhea mātou taua nei rakahau e whakahākai? How will the research be used?**

*Te manu e kai ana i te miro, nōna te kahere; te manu e kai ana i te mātauraka, nōna te ao!* *The bird that partakes of the miro berry, reigns in the forest; the bird that partakes of the power of knowledge, has access to the world!*

Over the past few years the New Zealand Government has done a lot of work to understand family and sexual violence, and to develop a whole of government approach to its prevention.

This research hopes to reduce the impact of violence and abuse by developing better ways for supports and services to respond to wāhine whaikaha, D/deaf and disabled women. The aim is to develop a model by listening to, and engaging with, wāhine whaikaha, D/deaf and disabled women and support services. This is called co-design and is an approach that will help bring to life a disabled person-led twin-track and rights-based approach to violence prevention and support services.

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

This research has three different, but interlinking, parts called strands:

1. Wāhine whaikaha Māori (Māori disabled women) and Kaupapa Māori Services
2. D/deaf and disabled women
3. Service providers in violence and abuse prevention and response

In this part of the research we want to talk to 20 people who self identify as women - wāhine whaikaha, disabled and D/deaf women - who have experienced family violence and/or sexual violence. You may or may not have reached out to services for support.

All participants must be over the age of 18 and be able to provide informed consent to participate.

**What will I do if I take part in this research?**If you do take part in this research we will meet with you three or more times over two years, 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 against Covid-19, but we can also arrange for the interviews to be conducted via Zoom or phone if needed or preferred.

In our first meeting/s with you, we will ask questions about:

* If and how you have used family or sexual violence services
* What it has been like for you to use these services
* How these services could work better with you and other disabled women
* If there were services specifically for disabled women, what they would need to offer

We will not ask you about your experience of violence or abuse.

We will then visit you again to check back with you about what we talked about the first time we met. This is so we can make sure what we have recorded is correct and you are happy with it. We will also share what we have heard from other women and services.

We will use the information provided by women and services through the three research strands to begin to make a model that can be used to improve violence prevention and support services for disabled women. During a third interview we will share this model with you and other women and services and ask for your feedback. This is the part where you help to co-design the model.

We will arrange any access support 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.

Each interview will take about 1.5 hours each. All individual participants will be given $200 (paid in two instalments over the 2-year project) as an acknowledgement of the time and expert knowledge you have given to this important research.

**What will happen with the information you share with us?**This research will take part under the korowai of our guiding values, which are:

* Whakamana (Ethical)
* Whakarakatira (Respectful)
* Whakawhanaukataka (Relational)

The research team will not talk to any other person about you or what you tell us, without your consent, unless you tell us that you or someone else is in danger and we are legally required to do so. This includes 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 then they will be written up. You will be able to read (or have read to you) what has been written from your interview and tell us anything you want changed. While we will use some of the things you tell us in the communications and publications that might be written or presented at conferences 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 a final report. It is important to note that publications from this project might be used by family and sexual violence service providers, Disabled People’s Organisations, community health and disability support services and the New Zealand Government to help them think about how to deliver rights-based violence prevention and support services.

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

**What if I get upset?**Because we know some participants might want to talk about things that are upsetting, we can arrange for you to talk to a trained counsellor or support service, free of charge.

You can also pull out of the project any time before the final report or other publications are written. No one can make you take part in this project either. It is totally up to you.

**What if I get hurt?**It is unlikely that you will be hurt or injured during this research. If you do get upset or hurt in any way because of your involvement in this research, we will give you information about how and where you can get support.

**What do I do if I want to take part?**There are a few ways you can tell us that you are interested in taking part.

* You can fill out the Participant Interest Form we have sent you. If you can fill it out yourself, you can send it back in the stamped self-addressed envelope attached to this form. That way no one will know you are thinking about participating.
* You can fill out a Participant Interest Form [online](https://corexmss43gf6x5cw7qm.qualtrics.com/jfe/form/SV_3rQywhtMdiVP4xM). Your responses will be sent directly to the research team.
* You can download and fill out a Word Doc Participant Interest Form, and email it to us, or you can contact the 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:

Eden Tuisaula (Kairuruku / Research Assistant)

Waea mai / Free phone: 0800 878 839

Īmēra mai / Email: etuisaula@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 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 and knowledge is important. You can still register your interest in this research, and remain updated on its progress.

**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 take part?**Nothing will happen. If you don’t want to take part, that is OK. No one can tell you that you have to take part in this research.

If you withdraw, it is your choice whether the researcher uses the information you have told them up until that time.

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

**What do I do if I want more information?**You can call or contact:

Brigit Mirfin-Veitch (Kaiwhakahaere/Director)
Waea mai / My phone number is: 0800 878 839 (free) or 027 479 2021
Īmēra mai / My email is: bmirfin-veitch@donaldbeasley.org.nz

Kelly Tikao - Kāi Tahu, Kāti Māmoe, Waitaha (Kairakahau Matua)
Waea mai / My phone number is: 027 482 6324
Īmēra mai / My email is: ktikao@donaldbeasley.org.nz

**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 research?**

All stages of this research will be overseen by a Māori Advisory Rōpū and Disability Advisory Group. They are working with us on this project to ensure that it is ethical and safe.

It has also been approved by the Northern B Health and Disability Ethics Committee (2022 FULL 12980). 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

**Kōrero Whakamārama**

We have chosen to apply the Kāi Tahu dialect when writing in te reo Māori. This means that the ng is replaced with a k (for example: whakarongo is changed to whakaroko). We have underlined the k whenever this has been applied.