**Disabled People’s Experiences of**

**Abortion Services in Aotearoa New Zealand**

**He Pānui Pāroko**

Interview Participant Information Sheet

**Tēnā Koe,**

We welcome you to participate in research about disabled people’s experiences of abortion services in Aotearoa New Zealand.

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

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

A group of disability researchers from the Donald Beasley Institute 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)
* Dr Kelly Tikao (Kairakahau Māori/Senior Māori Researcher)
* Dr Robbie Francis Watene (Kairakahau Matua/Senior Researcher)
* Dr Solmaz Nazari Orakani (Kairakahau/Researcher)
* Umi Asaka (Paewai Rakahau Teina /Junior Research Fellow)
* Eden Tuisaula (Kairuruku/Research Assistant)
* Lydie Schmidt (Kairuruku/Research Assistant)
* Jacinta Tevaga (Kairuruku/Research Assistant)

This research is funded by Manatū Hauora (Ministry of Health) 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.*

This research seeks to understand disabled people’s access to, and experiences of, a wide range of abortion services in Aotearoa New Zealand. The findings from the research will help the government and healthcare providers to address matters of disability rights, and deliver more equitable, inclusive and accessible abortion services.

The findings will also feed into the New Zealand Government's 5-year review of the Abortion Legislation Act 2020.

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

***Mā te roko, 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.*

Abortion is both a human right and a health issue. Under Article 25 of the United Nations Convention on the Rights of Persons with Disabilities, disabled people have the right to the highest attainable standard of health without discrimination on the basis of disability. This includes the same range, quality and standard of free or affordable health care and programmes as provided to non-disabled people, including in the area of sexual and reproductive health (United Nations, 2006).

While little is known about disabled people’s experiences of abortion services in Aotearoa New Zealand, international research shows that disabled people have a complex relationship with sexual and reproductive health. In particular, this includes access to abortion services, as well as the right to continue with pregnancy. To ensure that disabled people have access to the health services and supports they have a right to and deserve, there is an urgent and critical need to apply a disability lens to the delivery of abortion services.

**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!*

The findings of this study will help Manatū Hauora (Ministry of Health) to understand disabled people’s experiences of abortion services. A better understanding of disabled people’s experiences will enable Manatū Hauora to address matters of equity and access, and deliver more inclusive and accessible abortion services for tākata whaikaha, D/deaf and disabled people in Aotearoa New Zealand.

Key findings from this study will be translated into accessible formats and languages and be presented to Manatū Hauora by disability community representatives. They will be disseminated using a range of strategies including but not limited to: a publicly available report, disability-led hui, peer-reviewed journal articles, and presentations to key government officials.

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

In this part of this research, we want to interview 12 disabled people who have experienced a wide range of abortion services since 2020. This includes abortion-related mental health support or assessment, counseling, and contraception services. If you’ve wanted to access abortion services but weren’t able to, we’d also like to know about this too.

Family, whānau, aiga and/or close supporters of disabled people who have engaged with abortion services, but who cannot provide informed consent on their own behalf, are also invited to participate in an interview. Whānau and close supporters will be asked to share their own personal reflections on the abortion service interaction (and not speak on the disabled person’s behalf).

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

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.

**What will I do if I take part in this research?**If you are chosen to take part, you will be able to choose which researcher from the DBI will help you to share your experiences, and how you tell your story.

The researcher you choose will start by contacting you to arrange a time to meet. Where and when you meet will always be up to you.

If you live far away from each other, you might start to get to know each other over the phone. If it is impossible to meet in person, we will discuss your options with you.

At the first meeting with the researcher, they will answer any questions you have and make sure that you still want to take part.

To share your story, you and the researcher you’re working with will meet more than once. The first meeting will help you decide what kinds of things you want to talk about, and the things you want included in your story. Some of the things you and the researcher may talk about:

* Abortion service providers
* What is needed for abortion service providers to be accessible to and inclusive of disabled people.

Each meeting will take about 1-1.5 hours.

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

This research will take part under the korowai of our guiding values, which are:

Kā Mātāpono (DBI Research Values) will also underpin this important work:

* 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

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.

When you meet, your researchers will ask you if it is ok to record what you talk about. This will help the research team to write about what you and other people talked about. You can ask to have the recorder turned off whenever you want. 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.

We may also contact you in the future to confirm interview details, ask if we can speak with you further about the things you’ve told us, or update you on this study and further research opportunities in this study.

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 Manatū Hauora, Disabled People’s Organisations (DPOs), community health and disability support services and the New Zealand Government to help them think about how to deliver inclusive and accessible abortion 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 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 request a Participant Interest Form to be posted to you with a self-addressed envelope. That way no one will know you are thinking about participating.
* You can fill out a Participant Interest Form online [insert link]. 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 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:

**Lydie Schmidt** (Kairuruku / Research Assistant)

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

**Īmēra mai** / Email: lschmidt@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.

**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 about the project or Māori Cultural Support?**

**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?**

This research has also been approved by the Southern Health and Disability Ethics Committee (2023 FULL 18681). 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.

If you have any concerns about the ethics of this research you can contact the ethics Committee. The 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.

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**He Puka Whakaaetaka** Interview Participant Consent Form

If you want to take part in this research please read this form or have someone read it to you.

It tells you what your rights are as a research participant.

If you sign the form you are saying you want to take part.

I have read (or had read to me) the information about this research.

In giving my informed consent:

1. I understand the information I have been given.
2. I have had enough time to decide whether or not to take part in this research.
3. If I wanted to, I have been able to have a friend, family/whānau/aiga member or support person with me when I learned about this research.
4. I am satisfied with the answers I have been given about the research and I have a copy of this consent form and information sheet.
5. I understand that taking part is my choice and that I don’t have to take part if I don’t want to.
6. I understand that I can stop taking part at any time and I won’t be affected in any way.
7. I understand that if I withdraw from the research, it is my choice whether the researcher uses the information I have told them up until that time.
8. I consent to the research team collecting and processing the information I share with them.
9. I must only speak on my own behalf, and not on the behalf of others.
10. I understand that what is discussed within the interviews is private and must not be shared with anyone else.
11. I know that my participation is confidential and that no information that could identify me personally will be used in any reports of this research.
12. The research team will not talk to any other person about what I tell them, unless I, or someone else, is in danger.
13. I understand that the research team will talk to me first if they are concerned about my health or safety.
14. I consent to the interviews I participate in being recorded.
15. I understand I will get a copy of the final Project Report summary at the end of the research in my preferred format (please select one)

English (PDF)

Plain text (Word Doc)

Large Print

Te Reo Māori

New Zealand Sign Language

Easy Read

Braille

Audio

1. I know who to contact if I have any questions about the research.
2. I know the researchers might contact me in the future to confirm interview details, speak with me further, or update me on this study and further research opportunities.
3. I understand my responsibilities as a research participant.

I give my consent to take part in this research:

(circle choice) Yes No

Participant’s name: Signed:

Date:

Declaration by member of research team:

I have given an explanation of the research project to the participant, and have answered the participant’s questions about it.

I believe that the participant understands the research and has given informed consent to participate.

Research name/s: Signed:

Date