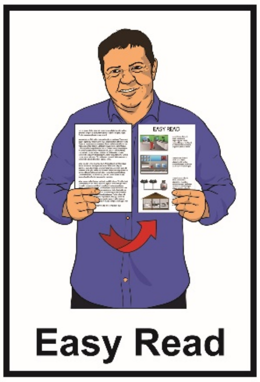
DONALD BEASLEY INSTITUTE

My experiences, my rights: Health and wellbeing project

Focus group information



What you will find in this booklet

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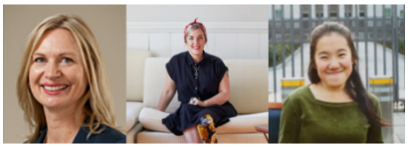

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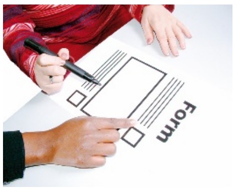
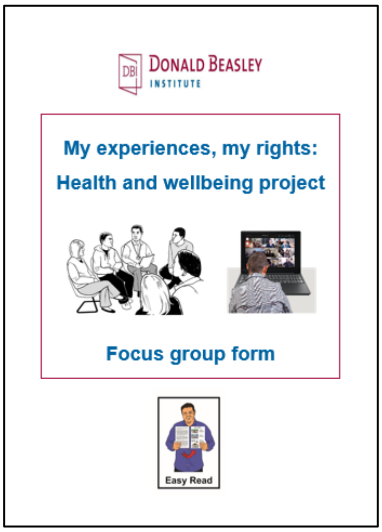


About this booklet

This is an Easy Read information booklet.

It is about some **research** that will be done about health and wellbeing services for disabled people.

Research is about looking into something to understand it better.



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Focus group form

Easy Read

This booklet will tell you about:

- who is doing the research
- what the research is looking at
- how the research will be done.

We will run **focus groups** as part of this research.

A **focus group** is a group of people that:

- get together
- talk about things they are asked to talk about.

The focus group will look at how disabled people feel about health care services they get.

The information in this booklet is to help you decide if you want to be part of a focus group.

You may find it helpful to:

- get someone to read this booklet with you
- take breaks and read this booklet in parts.

Who is doing the research?

This research will be done by 3 researchers from the Donald Beasley Institute.

They have all worked with disabled people for a long time.

They are:

- **Dr Brigit Mirfin-Veitch**

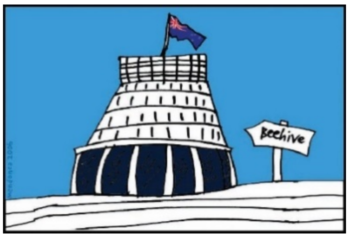
- **Dr Robbie Francis Watene**

- **Umi Asaka**

Dr Francis Watene and Umi are disabled people too.

What is the research about?

The **Disability Convention** is an international agreement that the New Zealand Government has signed.

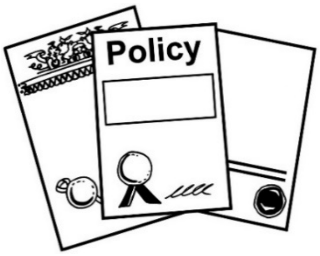


The **Disability Convention** sets out what the New Zealand Government should do to make sure disabled people:

- have the same rights as everybody else
- are able to live a good life.

The research will look at health and wellbeing issues for disabled people in New Zealand.

We would like to hear about the things you think we should look at.



We could look at things like **health policies and laws.**

Health policies and laws are rules made by the Government which health services must follow.

We could also look at things like your **rights**.

Rights are things that you are entitled to.

For example everyone has a right to things like:

- housing
- being kept safe
- having enough food to eat.

Sometimes disabled people do not get their rights.

This research will help make the health system better for disabled people in New Zealand.

Who can be part of the focus group?

Disabled people who are **18 years and older** can take part in the focus groups.

We would like to hear stories about:

- things that you like about your health services
- things that you do not like about your health services

- how health services can be made better.

You can let us know if you want to take part.

We will then pick people to take part in the focus groups.

How to take part in a focus group

Focus groups will be held in 2 different ways.

The focus groups will be held:

1. in different places in New Zealand

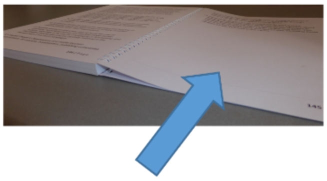
2. online using group video chat.

We can tell you more about how you can be involved in a focus group after you get in touch with us.

We want to talk to different kinds of groups of disabled people in each city.

We are doing this so different groups have the chance to share their stories.

We will hold 1 focus group for each group.



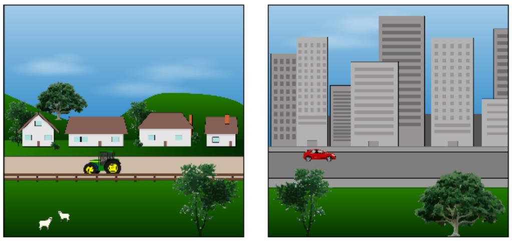
See which focus group you might be able to join on pages 15 - 19.

Focus group 1

For **focus group 1** we would like to talk to disabled people who are:

- Māori

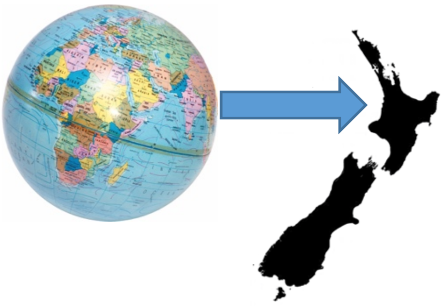
- Pacific Islanders
- living in **rural** areas.



Rural areas are places like towns in New Zealand that are part of big city areas.

For **focus group 1** we would also like to talk to disabled people who are:

- **immigrants**
- from **ethnic minorities**.



An **immigrant** is someone who was not born in New Zealand but lives here now.

Ethnic minorities includes people who are:

- Asian
- African
- Latin American.

Focus group 2

For **focus group 2** we would like to talk to:

- Deaf people

- family or supporters of people with **complex disabilities.**

Complex disabilities means that someone can have more than 1 disability.

For **focus group 2** we would also like to talk to people from the **LGBTQI+ Community**.

This includes anyone who is:

- lesbian
- gay
- bisexual
- transgender
- queer
- intersexual.

Focus group 3

For **focus group 3** we would like to talk to disabled people who have:

- mental health disabilities
- learning disabilities.

We would also like to talk to disabled people who are:

18 → 25

- 18 to 25 years old

- female.

Supports available

If we chose you to be in a focus group we will get you the **support** you need to come to the meeting.

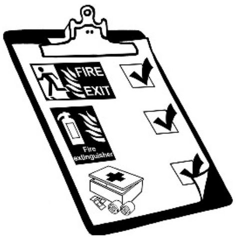
Support can include things like:

- a New Zealand Sign Language Interpreter

.

If you have a support person they can also come to the focus group.

We will not include stories shared by support people.



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

We will need to talk to someone else if we are worried about your health or safety.

What will happen at the focus group?

We will talk about lots of things to do with health services.

We want to find out **2 main things**.

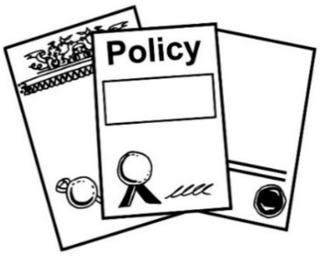
We want to find out about:

1. things that worry you about your health services

2. any bad things that have happened when you have used your health services.

We also want to know what you want us to look into.

This could be things like:



- the rules for how health care is given

- the way the health care service work.

We will **record** your stories.

We will ask you for information like:

- how old you are
- your cultural group
- you gender
- type of disability.

We can include Māori **cultural practices** like:

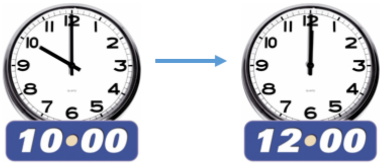
- starting and ending the focus group with **karakia**
- including **mihimihi.**

A **karakia** means blessing in the Māori language.

Mihimihi is said at the start of a meeting.

A **mihimihi** is a way to say:

- hello to people
- tell people who you are.



The focus group will take about **2 hours**.

We will give you something to eat at the focus group.

We will write down the main things we talked about in the focus group.

Giving your consent

You will be asked to sign a **consent form** before the focus group.

Consent means that you say yes to us using what you write in our survey.

You do not have to take part in the focus group.

It is also ok if you change your mind during the focus group

Your rights

This research has been agreed by the **Northern B Health and Disability Ethics Committee**.

This means that a group of people have made sure that the research is safe.

You have the right to:

1. ask questions about the research
2. only answer questions you want to.

What we will do with your information

We will:

- listen to the voice / video recordings
- type up what you said on a computer.

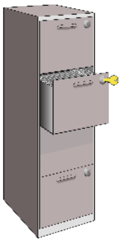
The documents they will type are called **transcripts**.

The transcripts will be ready a few weeks after the focus group.

You will be able to check your transcript.

We will use the information you give us to write reports.

We can give you a copy of the reports.



We will keep your information in a locked cabinet for 10 years.

This includes:

- voice recordings
- consent forms
- transcripts

This information will only be seen by the:

- research team
- transcribers.

You can see who the research team is on **page 7** of this booklet.

After 10 years this information will be destroyed.

Keeping your information private

Confidentiality means keeping the things you let us know about private and safe.

To keep confidentiality:

~~Your name~~

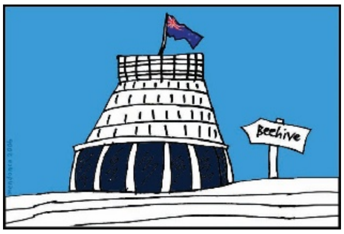
- we will not use your name in any of the research reports

~~Your name~~ ❯ Ms A
Mr B

- your name will be changed so that no ones who said what.

The research report will be read by:

- disabled people



- people working in government departments

- people working in health services.

How you can take part

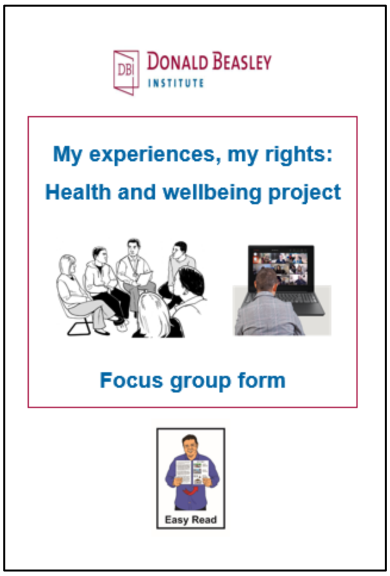
If you would like to take part you can:

1. Complete the form on our website by **Wednesday 8th of July 2020**.

www.donaldbeasley.org.nz/projects/disabled-person-led-monitoring-of-the-uncrpd/

2. If you are Deaf you can **email** a video to:

   uasaka@donaldbeasley.org.nz



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3. Complete the **Focus group form** that is part this booklet.

You can:

- email or post your form to us
- find our address on the form.

If you have any questions you can **phone** us on:

0800 878 839.

You can also ask a friend or family member to support you to fill out your form.

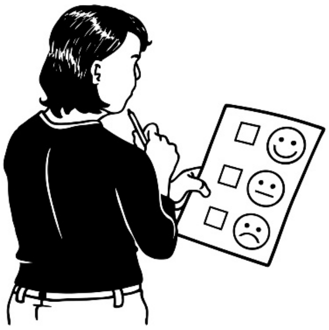
We will contact you once we have your form to check if you still want to take part.

If a lot of people want to take part in the focus group we will not be able to include everyone.

You can still share your story if you:

- are not chosen to be in a focus group
- cannot go to a focus group.

You can share your story by completing our online survey.



You can read more about the survey in our booklet **Information about our survey**.

You can find our booklet here:

www.donaldbeasley.org.nz/projects/disabled-person-led-monitoring-of-the-uncrpd/

More information

If you have questions about keeping safe in this research you can:

Phone: 0800 4 ETHICS

Email: hdecs@moh.govt.nz

For Māori health support:

Phone: 0800 878 839

Email:

admin@donaldbeasley.org.nz

If you want to talk to someone who is not part of this research you can talk the **Advocacy Service**.

The Advocacy Service can:

- listen to anything that you are concerned about

- give you ideas about what you can do

- support you to be heard when raising concerns.

To contact the **Advocacy Service**

Phone: 0800 555 050

Fax: 0800 2787 7678

Email:

advocacy@advocacy.org.nz

Website:

https://www.advocacy.org.nz/

How to get in touch with us

If you want to find out more information you can:

Phone:

0800 878 839

This a free call number

Free call number means it will not cost you any money to call this number.

To: sue.jones53@mail.com
From: l.stevens@mail.co.uk
Subject: Meeting Up

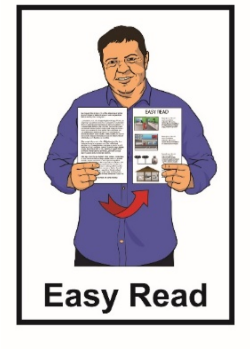
Dear Sue,
I am writing this email to

You can **email** us on

uasaka@donaldbeasley.org.nz

See our **website:**

www.donaldbeasley.org.nz/projects/disabled-person-led-monitoring-of-the-uncrpd/



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