



DONALD BEASLEY
INSTITUTE

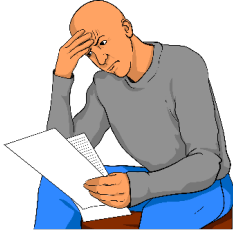


My Experiences My Rights: Supports and services



Strand 3:
Questionnaire information sheet

Before you read this



This is a long document.

While it is written in Easy Read it can be hard for some people to read a document this long.



Some things you can do to make it easier are:



- read a few pages at a time
- have someone support you to understand it like a:



- family member
- friend
- support person.

What you will find in this document

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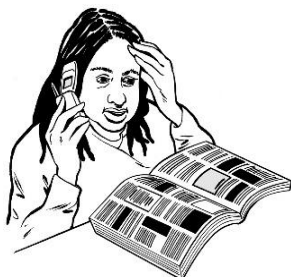


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What is this document about?



This Easy Read document is about being part of **research** done by the **Donald Beasley Institute**.



Research is when we get a lot of information together about something to learn about it.



The **Donald Beasley Institute** is a place that researches things to do with disability.

They are based in Dunedin in New Zealand.



In this document we will call the Donald Beasley Institute the **DBI**.



The research is about what disability supports and services are like in New Zealand.



DBI would like to invite you to answer a **questionnaire**.



You do not have to be part of the research if you do not want to.

Who is working on this research?



The people working on this research are:

- Dr Brigit Mirfin-Veitch
- Dr Robbie Francis Watene
- Umi Asaka
- Eden Tuisaula
- Aroha Mules
- Jacinta Tevaga
- Wally Noble
- Monica Leach



These people have all worked with disabled people in research projects for a long time.

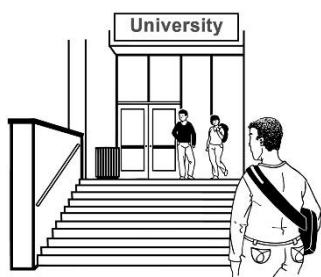


Most of the researchers are also disabled / Deaf people as well.

Disability support services



The New Zealand Government offers disabled people supports and services that support their human rights like the:



- right to have support
- right to have an education
- right to housing.



In the past disability supports have been run by:

- the Ministry of Health

or

- Accident Compensation Corporation / ACC.



Te Kaporeihana Āwhina Hunga Whara

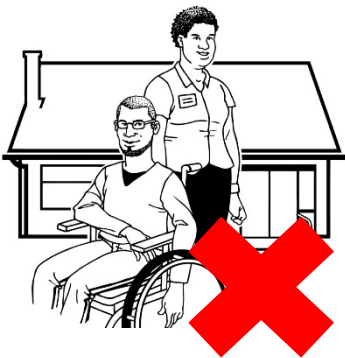


Some services have also been run by:

- the Ministry of Education
- the Ministry of Social Development
- District Health Boards.



Sometimes disabled people do not get the supports and services they need.



Sometimes disabled people miss out on supports / services.

The UNCRPD



The United Nations Convention on the Rights of Persons with Disabilities is an agreement by lots of different countries.



It is also called the **UNCRPD**.

The New Zealand Government has agreed to follow the UNCRPD.



This agreement says what governments need to do to make sure disabled people have the same rights as everyone else.



Disability rights include the right to have access to supports and services.

It is important to know:

- if the rights of disabled people are **respected**
- how the rights of disabled people are respected.



Respect is when someone shows they have thought about:

- who you are / the kind of person you are
- things that are important to you
- how you might feel.



Whaikaha – Ministry of Disabled People



Whaikaha – Ministry of Disabled People started in July 2022.

Enabling Good Lives

1 of the first things Whaikaha is going to do is set up a disability support system called Enabling Good Lives to all of New Zealand.



This research project will **monitor** the access disabled people have to supports and services when these big changes are happening.

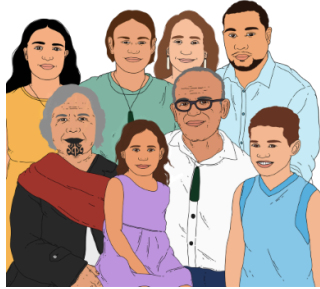


To **monitor** something means to check what happens.



As part of this research we want to hear from:

- disabled people
- family / whānau of disabled people
- close supporters of disabled people.



In this questionnaire we will ask you some questions about your experiences with things like getting:



- services
- care
- treatment like medicine / healthcare
- funding.



We want to know what disabled people think / feel about:



- the supports and services they have now / want to have
- changes to the disability support system
- the set up of Whaikaha – Ministry of Disabled people.
- if you live a good life
- if your human rights are met through supports and services
- if your human rights are met in a good way.



We also want to know what disabled people think / feel about how these changes are meeting the rights of disabled people under the UNCRPD.



At the end of our research we will have information about disabled people accessing disability supports and services.



The questionnaire will take about **30 to 60 minutes** to do.

Who can be part of the research?



We are asking people to answer a questionnaire.

To answer the questionnaire you must be:

- 18 years old or older
- able to give informed consent.



Informed consent is when you:

- are given information about something you have been asked to do
- understand that information, and
- can choose if you want to do what you have been asked to.





Supporters of people with **multiple and complex disabilities** can also answer the questionnaire to share their experiences and what they think.



Supporters may include whānau / aiga / family.



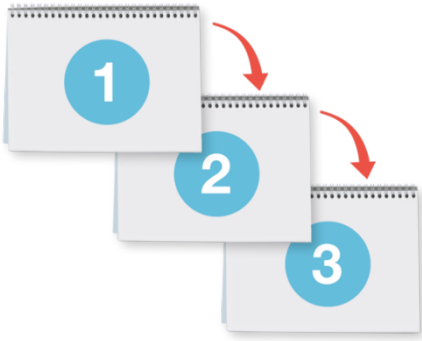
People with **multiple and complex disabilities** need a higher level of support.

Enabling Good Lives

The reason we are doing this questionnaire is so we can see what things are like:

- **before** there is Enabling Good Lives in all of New Zealand
- **after** Enabling Good Lives has started in all of New Zealand.





This research has 3 Parts to it.

For Part 1 we talked to leaders who were part of setting up:

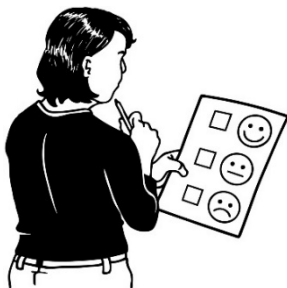


- Whaikaha – Ministry of Disabled People
- Enabling Good Lives in all of New Zealand.

Enabling Good Lives



In Part 2 we talked to disabled people in groups about specific supports and services topics.

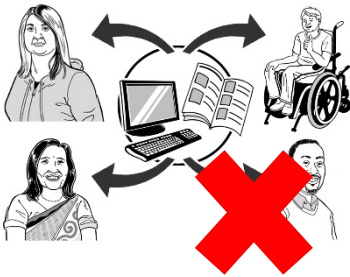


This Easy Read document is about Part 3 which is the Questionnaire.

What will happen with the information you tell us?



We will keep your information **private**.



Private means that we will not share what you tell us with anyone.



The research team will not talk to any other person about you without you saying it is okay unless:

- you might not be safe
- someone else might not be safe
- we are told by the law to do so.





We might share what you have told us with someone else if:

- you are being hurt
- you are hurting someone else.



We will talk to you about it before we talk with anyone else.



You can change what you answered in the questionnaire up to 2 weeks after you answered them.

We will do everything we can to make sure no one knows what you said.



We might use some of the things you tell us in:

- the Research Report
- other documents.

What the Research Report will be used for

There might be some time between:



- taking part in the research
- getting the final Research Report.



The final Research Report might be used by:



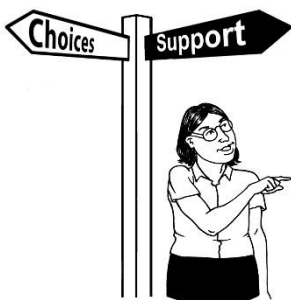
- Disabled Peoples Organisations
- community health services
- disability support services
- the New Zealand government
- the United Nations.



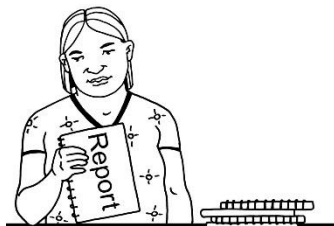


Organisations and the Government will use the report to:

- think about how they provide supports and services
- change the way they deliver supports and services.



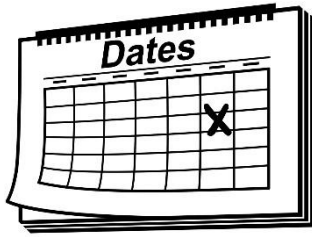
Any information you give will be used for this research only.



It will not be used for anything else.



If we write about what you have said we will make sure no one knows it was you who said it.



Everything you tell us will be kept safely at the Donald Beasley Institute for 10 years.



Everything you tell us for this research will be destroyed after 10 years.

This means after 10 years no one will be able to read it.

How you can take part in the research?



If you want to take part in the research you can answer the survey by:

- filling it out online at:

<https://tinyurl.com/4n9z7hy4>

or

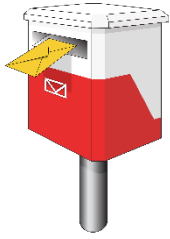
- downloading the Questionnaire in Word document form from our website:

<https://tinyurl.com/49u2axr6>



You can fill in the Questionnaire then send it to us by email at:

uasaka@donaldbeasley.org.nz



You can also send us the form by
post to:

Umi Asaka

The Donald Beasley Institute

Suite 4, Level 2

248 Cumberland Street

Dunedin 9016

New Zealand



If you use **New Zealand Sign Language:**



1. Go to the **SeeFlow Direct website:**

<https://seeflow.co.nz/direct>



2. Video record your answers on the website.
3. Your answers will be sent to us.

If you need support to fill out the questionnaire you can:



- talk to the DBI research team by phoning **0800 878 839**



- ask someone else to support you to fill out the form like a:

- friend
- family member
- support worker.



Other questions you might have



There are some questions we get asked a lot.

We have answered some of those questions below.



What happens if I am part of the research but I change my mind?

You can choose to stop taking part in the research at any time.



If you choose to stop being part of the research you can decide if the researcher uses the information you have told them.



What if I get hurt?

You are not likely to get hurt during this research.



If something in the research is upsetting you can talk with us about:

- how to access support
- where to access support.



Contact us



You can contact us if you need:

- more information about the research
- Māori health support with our Kairangahau Māori Research Associate Dr Kelly Tikao.



You can contact us by phone on:

0800 878 839



This phone call will not cost you any money.



You can also contact us by email at:

admin@donaldbeasley.org.nz

Who else can I contact for advice?



If you would like to know more about your rights during this research you can talk to a **Health and Disability Consumer Advocate**.



You can contact them by:

- **phone:**

0800 555 050



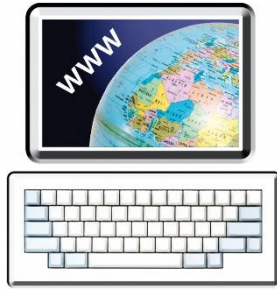
This number is **free** to call.



This means it will not cost you any money.



- **email:**
advocacy@advocacy.org.nz



You can also send them a message through the form on their **website** at:

<https://advocacy.org.nz/contact/>



**Health and
Disability Ethics
Committees**

If you are worried about any ethical issues to do with this research you can contact the **Northern B Health and Disability Ethics Committee**.



The Northern B Health and Disability Ethics Committee is a group of people who make sure that:

- our research is safe
- that we will work with people in a respectful way.





You can contact the Ethics
Committee by:

- phone:

0800 4 38442

- email:

hdecs@health.govt.nz





This information has been written by
The Donald Beasley Institute.



It has been translated into Easy Read
by the Make it Easy Kia Māmā Mai
service of People First New Zealand
Ngā Tāngata Tuatahi.



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