



**DONALD BEASLEY**  
INSTITUTE

# **My experiences, my rights: Health and wellbeing project**



## **Information about the study interviews**



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# About the study



The Donald Beasley Institute is looking into **health and wellbeing** of disabled people.



**Health and wellbeing** means things like:

- how we feel about ourselves
- looking after our bodies
- getting the support we need.



Sometimes disabled people do not get good health and wellbeing:

- services
- treatment
- support.



We are looking for people to take part in a **study** so we can get more information about these things.



A **study** is how we find out the information we need.



We want to find out:

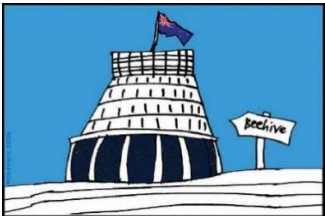
- what disabled people think about the services they get
- what services disabled people would like to get in the years to come.



# Why are we doing this study?



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



The **convention** sets out what the governments should do to make sure disabled people:

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





The United Nations Convention on the Rights of Persons with Disabilities is also called the **UNCRPD**.



One of the rights in the UNCRPD is the right to a good level of health without **discrimination**.



**Discrimination** is when disabled people are treated unfairly because of their disability.



It is important to understand if disabled people are getting this right.



## Who is doing the study?



The study 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**



Robbie and Umi are from the disability and mental health community.

Also working as part of the Donald Beasley study team are:



- Dr Solmaz Nazari



- Eden Tuisaula

Solmaz and Eden are from the disability and mental health community.



They will be doing the **study interviews** with disabled people.



A **study interview** is where we ask disabled people questions as part of the study.



There is more information on **page 12** about the study interviews.

## What we have done this year



Earlier this year we talked to more than 100 people.



We asked them what issues they wanted us to look at as part of this study.



We spoke with:

- disabled people
- family and whānau of disabled people
- support workers.





We now want to talk to more disabled people:

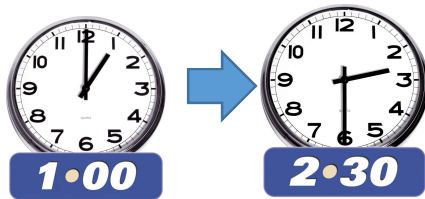
- from different places around New Zealand
- have different kinds of disabilities.



# About the study interview



A **study interview** is where we ask you questions as part of the study.



The study interview will take about 1 hour and 30 minutes.

You will:



- talk to just one person doing the study interview

or



- talk to the person doing the study interview as part of a group.



You can have a support person with you at the interview.



At the moment because of **COVID-19** there are some rules about:

- group meeting sizes
- travel.



**COVID-19** is a virus that can make people sick.



These rules mean we may need to do some of the interviews online using Zoom.

**Zoom** is a way of having lots of people talking in a meeting using their computer.



We may be able to interview you in person in a place you feel that would be better for you.



We can set up any supports you need like:

- New Zealand Sign Language Interpreters
- access to buildings.

# What will happen at the interview?



In the interview we will ask about things like:



- getting the information you need about health and wellbeing services
- getting the healthcare you need
- how different rules and ways of doing things affect you getting the services you need
- whether services cost too much
- how COVID-19 has changed things to do with health and wellbeing for you.





You will also be able to talk how you get support with your health and wellbeing.



You will be asked if there are any cultural things that we need to think about.



For example if you are Māori you may be more comfortable if the person doing the study interview knows about tikanga Māori.



We can include Māori cultural things like:

- karakia
- mihi mihi.



We will do a sound or video recording of what you say.

You can ask us to stop recording at any time.



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



We will give you a \$50 supermarket voucher for taking part in the interview.



The \$50 supermarket voucher is a koha or donation to thank you for your time.



We may contact you after the interview to see if you want to take part in another interview.

# Giving consent



In the study interview we will ask for your **consent**.



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



If you do not want to take part in this study that is ok.

You do not have to do any study you do not want to.



If you do not want to take part but want to know about future studies you can let us know.



If you start to take part in the study  
but want to stop that is ok.



You can stop at any time.

# Your rights



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



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



You have the right to:

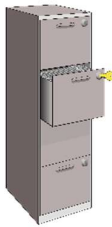
1. ask questions about the study
2. only answer questions you want to

# What we will do with your information



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.

Only the people doing the study will see your information.

**10 years** →



After 10 years this information will be destroyed.

# Keeping your information safe



**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 study reports

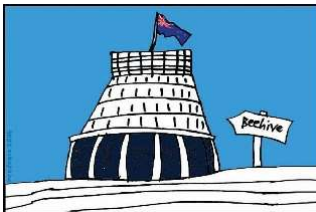
~~Your name~~ ➤ Ms A  
Mr B

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



The study report will be read by:

- disabled people
- people working in government departments
- people working in health services.

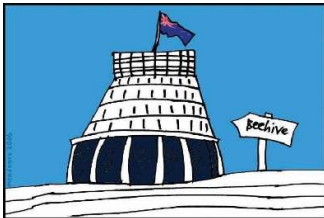


# What happens after the study



After the study interviews we will have some good information about:

- the experiences disabled people have of health and wellbeing
- ways things can be done better in the future.



We will give this information to:

- the New Zealand government
- the United Nations.





## More information



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

**Phone:** 0800 4 ETHICS

**Email:** [hdecs@moh.govt.nz](mailto:hdecs@moh.govt.nz)



For Māori health support:

**Phone:** 0800 878 839

**Email:**  
[admin@donaldbeasley.org.nz](mailto:admin@donaldbeasley.org.nz)



If you want to talk to someone who is not part of this study you can talk to 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](mailto:advocacy@advocacy.org.nz)



**Website:**

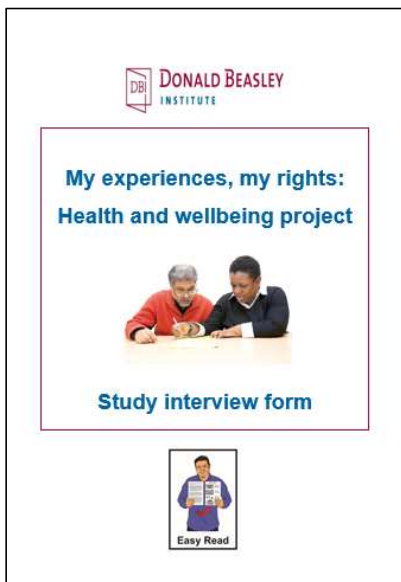
<https://www.advocacy.org.nz/>

# How to take part



If you want to take part in an interview you can find more information on our website:

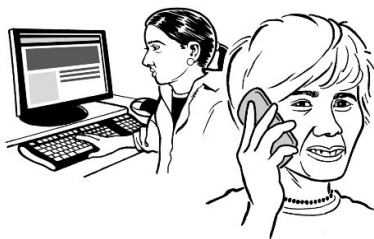
**[www.donaldbeasley.org.nz/projects/  
disabled-person-led-monitoring-of-the-uncrpd/](http://www.donaldbeasley.org.nz/projects/disabled-person-led-monitoring-of-the-uncrpd/)**



There is an Easy Read form that you can fill in called:

**Study interview form.**

You can find the Study Interview form on our website.



We can support you to fill in the form.

You can contact us by **phone**:



**0800 878 839**

This a free call number.



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



You can **email** us at:

**[uasaka@donaldbeasley.org.nz](mailto:uasaka@donaldbeasley.org.nz)**



To take part in a study interview you must send us your form by:

- 5 pm
- **Friday 30 October 2020.**

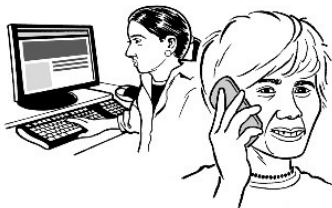


If a lot of people want to take part in the study we may not be able to talk to everyone.



If we cannot talk to you we:

- still think what you have to say is important
- will let you know how the study is going.





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