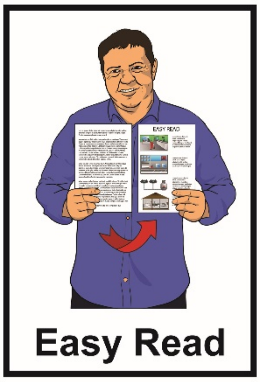
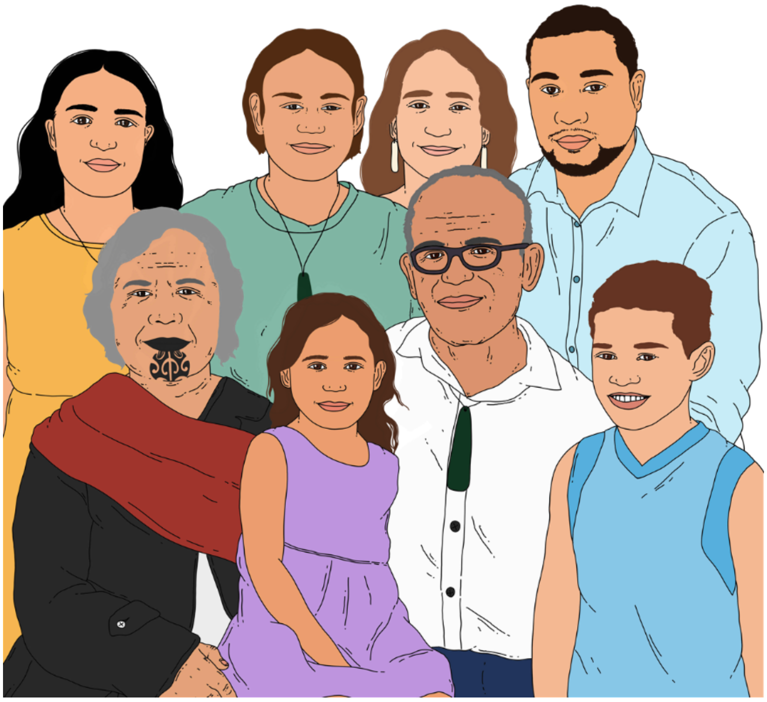
DONALD BEASLEY INSTITUTE



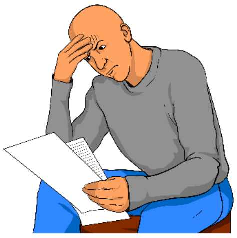
Disability, home and family in a multicultural context:

Phase 1



Participant Information Booklet

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 to support you understand it.

You can ask someone like:

- a friend
- a family member.

What you will find in this booklet

Page number:

What is this document about?

This Easy Read document is about a **study** that the **Donald Beasley Institute** is doing.

The Donald Beasley Institute does **research** on the lives of disabled people.

Their offices are in Dunedin.

A **study** is looking for answers to a question you have and writing down what you find out.

Research is when you look for a of answers about a subject.

Research is often done by doing a lot of **studies**.

This study is about how people who are part of the disabled community think about their:

- homes
- families.

What is this research about?

We want to find out how people in the disability community think about:

- home

  and

- family.

There are lots of kinds of families like families:

- where there is 1 parent

- where the parents are not married

- where the grandparents live with their children

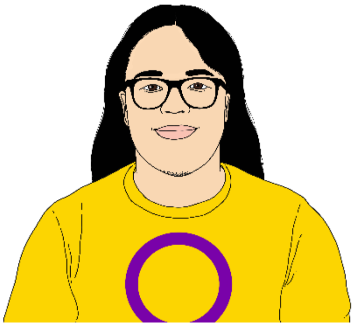
There are also families that:

- are taking care of children for other people

- have stepparents

- are **rainbow families**.

A **rainbow family** is a family that includes people who are part of the **LGBTTIQ+** community.

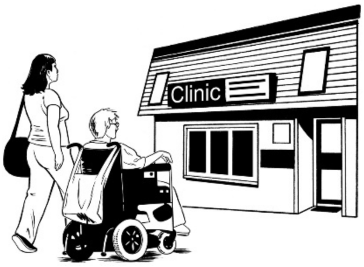


LGBTTIQ+ stands for people who are:

- Lesbian
- Gay
- Bisexual
- Transgender
- Takatāpui
- Intersex
- Queer
- and others.

The experiences disabled people have with their home and family can be changed by their:

- disability



- health
- wellbeing

- culture
- support workers
- relationships with:

  - friends
  - family.

We will be asking questions by using the **United Nations Convention on the Rights of Persons with Disabilities**.

The **United Nations Convention on the Rights of Persons with Disabilities** is a law lots of countries have agreed to.

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

It says what governments must do to make sure disabled people get the same rights as everyone else.

Part of the UNCRPD says that disabled people have the right to a

- home

and

- family.

We want to find out what it now means in New Zealand to have the right to a:

- home

and

- family.

Who is doing the study?

Researchers from the Donald Beasley Institute are doing this study.

A **researcher** is someone who looks for answers about something they have questions about as their job.

The 4 researchers leading this study are:

- Dr Brigit Mirfin-Veitch
- Dr Robbie Francis Watene
- Dr Solmaz Nazari
- Umi Asaka.

They will be assisted by other researchers from the DBI.

3 of the researchers leading the study:

- are disabled
- have done a lot of research into disability rights.

These 3 researchers are:

- Dr Robbie Francis Watene
- Dr Solmaz Nazari
- Umi Asaka.

Who can be part of the study?

To be part of our study you need to:

- be over 18 years old
- give **informed consent**
- be happy to answer the questions in the **questionnaire**.

Informed consent means you understand what you are agreeing to do.

A **questionnaire** is a list of questions that need to be answered to be part of our research.

To be part of the study you also need to:

- have a disability

or

- be family / whānau of someone with a disability

or

- be a support person for someone with a disability.

About the questionnaire

If you want to be part of the study you need to fill in the questionnaire.

The questionnaire will ask you questions about:

- your family / whānau
- the right to have a home
- the right to have a family
- what you think about family / whānau.

You will also be asked things about yourself like:

- your age
- your gender
- what your disability is
- your **ethnicity**.

Ethnicity means what culture you are part of like:

- Māori
- Pasifka
- Chinese
- European.

The questionnaire will take up to **1 hour** to finish.

You can fill out the questionnaire online at:

http://surl.li/cjhqe

You can contact us if you would like to answer the questionnaire:

- by email
- over the phone

- in print

- over Zoom.

Privacy

We keep everything you tell us **private**.

Private means that we do not share anything you tell us with other people unless you say we can.

The only people who will be able to see your information will be:

- the DBI research team
- our **transcribers.**

Transcribers are people who write down information for our study.

The only times we will share your information with someone else is if:

- you are not safe

- someone else is not safe
- the courts tell us we need to.

We will talk with you before we tell anyone else your information.

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

- our report
- other articles.

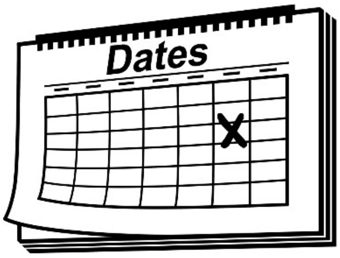
We will not use anything that will tell other people who you are.

You have **2 weeks** after you fill out the questionnaire to:

- look at what you answered
- change your answers.

We keep what you tell us safe by using numbers called a **code system**.

A **code system** keeps your information safe by using a number instead of using your name.



We keep all the information you share will us at the Donald Beasley Insistute for **10 years.**

We get rid of all the information you have given us after 10 years.

Taking part

You do not need to be part of the study if you do not want to.

No one can tell you that you have to take part.

If you want to know about other studies we might do later then you can contact us to ask us to tell you about them by:

- phone
- email.

Changing your mind

Sometimes people who have been a part of the study decide they do not want to keep being part of the study.

It is ok if you choose to stop being part of the study at any time.

If you choose to stop being part of the study:

- nothing bad will happen
- you will not get in trouble.

If you choose to stop being part of the study then you can choose if we:

- use the information you have already told us

- do not use the information you have already told us.

Staying safe

It is not likely that you will get hurt as part of this study.

If you feel upset about anything about our study when taking part then we will talk with you about:

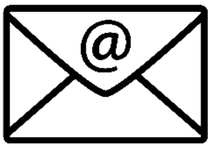
- how to get support

- where to get support.

How to contact us

If you have more questions you can contact our DBI Research Team by:

- email:



admin@donaldbeasley.org.nz

- phone:

0800 878 839

This phone number will not cost you any money to call.

You can find out more information on our website at:

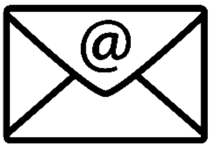
https://www.donaldbeasley.org.nz/projects/disability-home-and-family-in-a-multicultural-context/

Māori health support

For Māori research support you can contact Dr Kelly Tikao.

Dr Kelly Tikao is our Kairangahau Māori Reseach Associatte.

You can contact Dr Kelly Tikao by:



- email:

admin@donaldbeasley.org.nz

- phone:

0800 878 839

This phone number will not cost you any money to call.

Health and Disability advocates

If you want to talk to someone who is not part of our study then you can contact a health and disability advocate by:

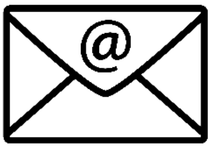
- fax:

  0800 2787 7678

- phone:

  0800 555 050

These numbers will not cost you any money to use.



You can email the health and disability advocate at:

advocacy@advocacy.org.nz

You can find more information about health and disability advocates on their website at:

www.advocacy.org.nz

Who to contact if you are worried about the study

If you are worried that the way we are doing our study is not safe then you can contact the **Northern B Health and Disability Ethics Committee**.

The Northern B Health and Disability Ethics Committee checks that studies:

- are going to be done in a safe way
- are going to work with people in a respectful way.

You can contact the Ethics Committee by:

- phone:

0800 438 442

- email:

hdecs@moh.govt.nz

This information has been written by Donald Beasley Institute.

It has been translated into Easy Read with advice from the Make It Easy service of People First New Zealand Inc. Ngā Tāngata Tuatahi.

The ideas in this document are not the ideas of People First New Zealand Inc. Ngā Tāngata Tuatahi.

Make It Easy uses images from:

- Changepeople.org
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- Huriana Kopeke-Te Aho.