



Flourishing Together



Flourishing Together: Including disabled people in health policy development

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PARTICIPANT INFORMATION SHEET – ONLINE INTERACTIVE SURVEY

Tēnā koe, hello!

You are invited to take part in a research study asking disabled people about the **things that made it easier or harder for them to find a home that worked well for them and their families.**

Other **terms for 'disabled people'** that you may be more familiar or comfortable with include 'person living with a disability', 'tāngata whaikaha Māori' or 'whānau hauā'. Some people prefer to say they have an impairment, or live with the ongoing impacts of an injury or illness.

Please read this information sheet carefully to decide if you want to participate. This information sheet will explain the research, and what your participation would involve.

- **Taking part is your choice.** If you don't want to take part, you don't have to give a reason. Whether you take part or not, will not advantage or disadvantage you in any way.
- Before you decide whether you want to take part, please **discuss the study with other people**, such as family, whānau, and friends. Also, feel free to ask the researchers any questions you might have about the study.
- If you agree to participate in this study, you will be asked to **indicate your consent** within the online survey.
- You can start the survey and then change your mind. You can **withdraw from the study** at any time.

WHO IS INVOLVED WITH DESIGNING AND RUNNING THE STUDY?

The study is being coordinated by researchers at the **University of Otago**. You can find out more about us at the end of this information sheet.

However, the ideas for planning and conducting this research are coming from **people who experience disability**.

We are working **closely and collaboratively with a group of around 20 disabled people from across NZ** to design the research, make sure you are asked the best questions (and in the best way), and help us make sense of answers you provide.

WHY ARE WE DOING THIS WORK?

The overall aim of the research is to explore ways to better **include the voices and experiences of disabled people in health-related policy** within NZ.

We are developing **methods and tools that allow disabled people to share their experiences and expertise** in meaningful ways.

To develop these methods, we are exploring one policy area – **what makes it easier or harder for disabled people to have choices and be in control when accessing a home that works best for them and their families?**

We are interested in policies, processes and systems that allow disabled people and their whānau to **self-manage and enact choices [mana motuhake]** in relation to **kāinga and papakainga** [housing and home].

We are therefore inviting you to do two things (at the same time) within this study:

- Help us **try out an online tool** that we have developed for gathering stories and experiences from a wide range of disabled people.
- In this tool, **share your own housing and home stories** so that the research team can learn from your experiences.

WHAT WILL WE DO WITH THESE RESEARCH FINDINGS?

The tools developed as part of the research will be gathered together into **a toolbox to support policy developers and government advisors to engage more meaningfully with disabled people** in the future.

The findings from this research will be presented to:

- **Organisations that are involved in decision-making** (e.g., Whāikaha | Ministry for Disabled People and other central and local government bodies).
- **Housing agencies and organisations** (i.e., including Kāinga Ora and Iwi-housing organisations).
- Organisations and agencies representing **disabled people**.

You can access more detailed information about the study here: www.flourishingtogether.co.nz

WHO IS FUNDING THIS PROJECT?

- This 3-year research project is funded by the Health Research Council (HRC) Emerging Researcher fund.
- The study has been approved by the University of Otago Human Ethics Committee (H21/099).

WHO CAN TAKE PART?

We are wanting to gather thoughts and experiences from a lot of different disabled people.

- We would like anyone who **identifies as a disabled person**, or who experiences disability to take part.

Other terms for disabled people that you may be more familiar or comfortable with include 'person living with a disability', 'tāngata whaikaha Māori' or 'whānau hauā'. Some people prefer to say they have an impairment, or live with the ongoing impacts of an injury or illness. You may have experienced **disability since birth**, or due to **illness or injury** later in life.

- If you are **whānau or family of a disabled person**, then you are also welcome to take part.
- You will need to be over **16 years of age** to take part in this research.

WHAT WOULD WE LIKE YOU TO DO?

You will be asked to tell us what you think about the research topic in two main ways:

1. You will be asked to **introduce yourself and then answer 10 'story' questions**. This means that you can tell us what you think using words, ideas, stories, and pictures.
2. You will then be asked to fill in some **'number' questions** so that we know more about who answered the questions. This information can also help us explain the range of people who responded, and how varied they are.

You do not need to answer all of the questions. You can choose to answer as many of these questions as you like.

More information about the types of questions, and how we would like you to answer them, can be found on the Flourishing Together study website: www.flourishingtogether.co.nz.

Because this is a new approach to gathering disabled people stories, at the end of the survey you will also be offered the opportunity to **tell us more about what worked and what didn't work**. We are keen to know what was helpful and what could be improved about this approach. It is **entirely your choice** whether you complete this section.

HOW WILL YOU BE ABLE TO RESPOND?

An online, accessible survey will ask you the questions, and allow you to respond in a format of your choosing. We are using an accessible survey platform that allows people to not only tick boxes but to tell their stories in ways that they feel comfortable.

As part of developing this online tool, we are also modifying the survey platform with a few new accessibility features. It is a work in progress, and we really value your feedback and ideas!

Languages: You can access the questions in **English**. **Te reo Māori and NZ Sign Language** materials are also being prepared and will be available from February 2024.

The tool is also set up so you can choose the type of format that best meets your needs.

- The **question accessibility format options** currently available are:
 - Read aloud [text-to-speak; choose your speed]
 - Easy read
 - Videos with captioning
 - NZ Sign Language [from February 2024]
- The **response accessibility options** currently available are:
 - Text
 - Use of voice-to-text software from your own device (e.g. Dragon)
 - Voice recording (i.e., a voice memo)
 - Upload a file (e.g an image, an audio file or a video file)

Any **audio, photographic or video materials** you upload to help share your experiences will only be accessed and used by the research team, and will not be made publicly available in any way.

Please don't hesitate to **contact us if these options will not work for you** – we are more than happy to explore other ways to gather your thoughts and ideas.

ARE THERE ANY RISKS OR COSTS INVOLVED?

There is **no cost** to you, except for your time.

Based on the piloting of the survey, we know that it could take people up to **2 hours to complete** the survey if **all the questions** are answered.

We **do not** expect people to spend this much time. Here are some ways that we hope will reduce the time people spend responding.

1. We **do not expect everyone to answer all of the questions** – only those that are most relevant to them. If people answered 2-3 of the 'story' questions, we expect the survey would take 20-30 minutes.
2. We are also making responding as possible for people by offering them the **option of speaking their responses**, rather than typing their responses. We think that this will make the process of sharing your stories a lot quicker.

3. Your responses can be **added in gradually over time**. We know some people will need to add their ideas in shorter bursts, so the survey will remain 'open' to you for 1 month. You can **re-access your survey** over this period, responding at a pace and at times that work best for you.
4. You can **ask others to help** you complete the survey.

We know that talking about your experiences can be difficult. If you would **like to talk to someone** about any issues or concerns, you can access an independent health and disability advocate via the Health and Disability Commission. Their contact details are on the last page of this information sheet.

CAN I WITHDRAW FROM THE STUDY?

You can **withdraw from the study at any time**, for whatever reason. It is your choice.

However, **any information that you have provided already within the online tool will be accessed by the researchers and used in the study**. Because the survey is anonymous, we are not able to link your information to you – and, therefore, cannot delete it.

WHAT WILL HAPPEN TO THE INFORMATION COLLECTED?

All of your responses and information will be **confidential** to the research team.

To allow you to access the survey over a period of time, **Accessible Surveys (who host the online tool) will retain a copy of your computer address (IP Address)** for 1-month after you first access the survey. At the 1-month, this information is automatically deleted.

Because the survey is anonymous, we will not know your name. However, any other **personal information that could identify you will be removed** from your responses.

If we **use any parts of your responses** in the research reports, we will make sure you **cannot be identified**.

Your responses will be **downloaded and stored** in secure password-protected files on University of Otago data-storage systems. Participant codes will be used to keep track of participants' responses, and data will be stored in a de-identified format.

- **Written text:** Participant codes will be used instead of names. The text will be manually checked to remove details that may potentially lead you or others to be identified.
- **Audio files:** All audio files will be transcribed, and the transcripts deidentified.
- **Visual images or video files:** The audio of the video files will be transcribed and all transcripts de-identified. Within the survey you will be reminded to not upload any photos or images that could identify other people. We will also blur or redact any part of the image or file that identifies you before storing it.

Use of data for future studies:

There is the possibility that responses from this study could be useful for future research. For example, we may want to explore in more detail the housing situations of people who completed this survey by analysing the 'number responses' in more depth. Therefore, we will also **request your consent for the use of de-identified data in future studies**. You **can decline to give this additional consent, but still participate in the survey**. This means that we will use your responses in this study, but not use your responses in future research.

Any data collected as part of this study, will be kept for at least 10 years and then destroyed.

HOW DO I AGREE TO TAKE PART IN THE STUDY?

You will be asked to **give your consent** within the online survey.

To give consent and start providing your responses go to <https://www.flourishingtogether.co.nz/survey> and **click on the red link**.

WHO CAN I CONTACT ABOUT THIS STUDY?

If you would like to **talk to a researchers about this survey**, please email, phone, text or use WhatsApp to contact one of the people listed below:



Susan Wadsworth
Researcher | Disabled Person
sueboo2003@hotmail.com
Cell: 022 672 0230



Jasjot Maggo
Researcher
jasjot.maggo@otago.ac.nz

If you have any **questions, concerns or complaints** about the way this research is being conducted, you can contact the primary researcher:



Dr Rachelle Martin
Principal investigator; Flourishing Together Project
Senior Lecturer, Rehabilitation Teaching and Research Unit
University of Otago Wellington
Cell: 021 22 333 62
rachelle.martin@otago.ac.nz

Do you want to talk to **someone not involved** in the study? You can contact an **independent health and disability advocate** at Health and Disability Commission

Phone: 0800 555 050

Email: advocacy@hdc.org.nz

This study has been approved by the University of **Otago Human Ethics Committee (Health)**. If you have any **concerns about the ethical conduct of this research**, you may contact the Committee through the administrator:

Phone: +64 3 4798256

Email: gary.witte@otago.ac.nz

Any issues you raise will be treated in confidence and investigated. You will be informed of the outcome.

CONSENT FORM FOR ONLINE INTERACTIVE SURVEY

NOTE: You will be asked to provide consent online within the online survey tool. However, the following is what you are consenting to.

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Principal Investigator: Dr Rachelle Martin (rachelle.martin@otago.ac.nz)

- I have read the information sheet about this study and **understand the research project's aims**.
- I have had **sufficient time to talk about participating** in the study with other people of my choice.
- All my **questions about the project** have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
- I know that my **participation in the project is entirely voluntary** and that I am free to **withdraw** at any stage. Because the survey is anonymous, **any information we have provided up to this point will be included** since we cannot identify your specific data.
- If I feel hesitant or uncomfortable with any of the questions, I may **decline to answer** them and may **withdraw** from the project without disadvantage of any kind.
- I understand the nature and size of the **risks, discomfort or harm**, which are explained in the Information Sheet.
- I know that when the project is completed, **all personal identifying information will be removed** from the paper records and electronic files representing the data from the project. These will be stored in secure storage for at least ten years.
- I understand that any **audio, photographic or video materials** I upload will only be accessed by the research team as data and will not be made publicly available in any way.
- I understand that the project's results may be published, and I agree that any **personally identifying information will remain confidential** between myself and the researchers during the study. I will not appear in any spoken or written report of the study.

Signature of participant:

Date:

CONSENT FOR FUTURE USE OF DATA:

- I consent for the use of the data I provide within this study, being used in a **de-identified** manner in **future studies**.

Signature of participant:

Date: