



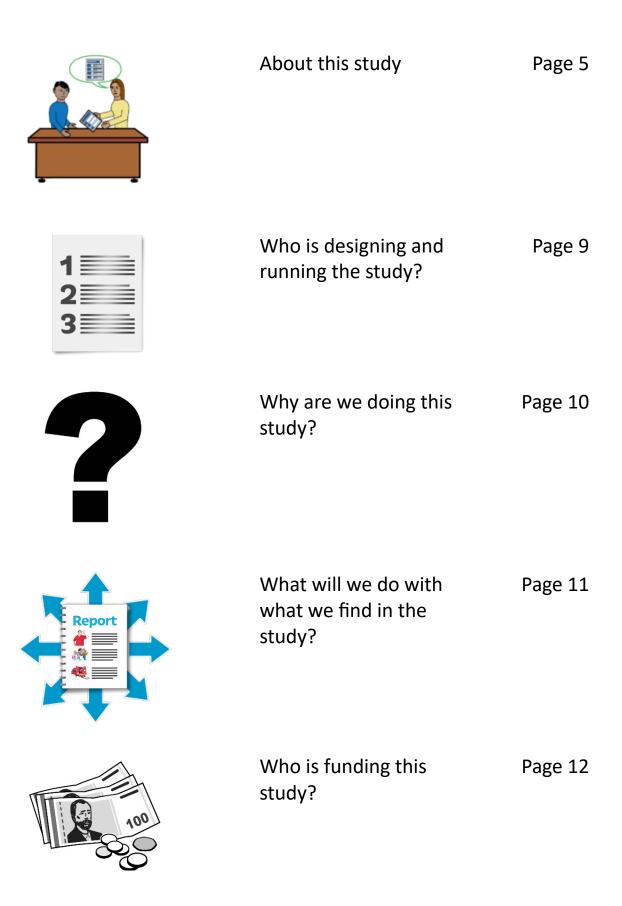
# Flourishing Together:

# Including Disabled People in Health Policy Development

Easy Read Participant Information Sheet



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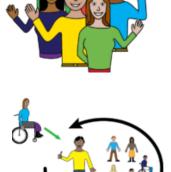
Who can I talk to about Page 28 this study?



Consent

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#### About this study



Tēnā koe, hello!

You are invited to join a study.



This study asks disabled people **what makes it easier or harder to find a home** that works for them.



Other terms for 'disabled people' that you may like more are:

- 'person with a disability'
- 'tāngata whaikaha Māori'
- 'whānau hauā'
- 'person with an impairment'
- 'person who lives with ongoing impact of an injury or illness'



Please read **this information sheet** to decide if you want to take part.



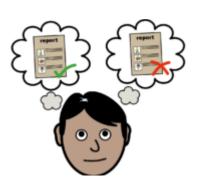
This sheet will explain the study.



This sheet will explain what **taking part means** for you.



Taking part is **your choice**.



You **do not have to tell us why** you do not want to take part.



There is **no problem** if you do not take part.



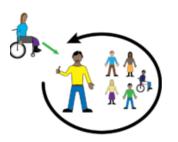
Before you decide if you want to take part, **talk to people** about it.



These people could be family, whānau, and friends.



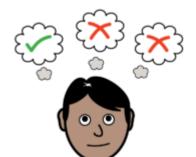
Please feel free to **ask the researcher team** any questions you have about the study.



Do you want to take part?



Then you will have to give **your consent** to join the study.



You can **start the survey**, and then **change your mind**.



You can stop doing the study from the study at any time.

The researchers will still be **able to see what you have already said or written** up to that point.

### Who is designing and running the study?



The study is led by a team of researchers at the **University of Otago** and the **Burwood Academy Trust.** 



The plan and ideas for how to run this study **come from people who experience disability.** 



We have **20 disabled people** across NZ who are helping us to create this survey.



This is to make sure we **ask the best questions**, and **understand your answers**.

#### Why are we doing this study?



We want **the voices of disabled people** to be included in health policy in New Zealand.



We are trying new ways for **disabled people to share their voice** and stories.

We want their stories to **change how things work** for disabled people.



We are looking at **what makes it easier or harder** to have choice with your house.



We are interested in **what helps you to be in charge** of decisions about your home.



We ask you to help us with this study in two ways:

- 1. **Try out an online tool** that we have made to hear your stories.
- 2. Share your stories so the researchers can learn from you.

# What will we do with what we find in the research?



The online tools we make in this study will be **used in the future.** 



This will help people to **listen well to disabled people** in the future.



What the researchers find will be given to:

- Organisations involved in **decision**making
- Housing Agencies and organisations
- Organisations and agencies who represent disabled people.

Learn more about the study at www.flourishingtogether.co.nz

#### Who is funding this study?

#### hrc nz

This research project is funded by the Health Research Council (HRC) Emerging Researcher fund.



This study has been approved by the University of Otago Human Ethics Committee (H21/099).

#### Who can take part?



We want to gather the stories from lots of different types of disabled people.



We want anyone who calls themselves a disabled person or experiences disability to take part.

Other terms for 'disabled people' that you may like more include:

- 'person with a disability'
- 'tāngata whaikaha Māori'
- 'whānau hauā'
- 'person with an impairment'
- 'person who lives with ongoing impact of an injury or illness'

**Your health condition** is not important for this study.



Are you whānau [family or support person] of a disabled person?

You **can** also take part.



You need to be **over 16 years** old to take part.

#### What would we like you to do?



You will be asked to tell us **what you think** in a 2 main ways.

- 1. Story questions
- 2. Number questions



First, you will be asked to **introduce** yourself.



Then you will be asked **10 story questions.** 

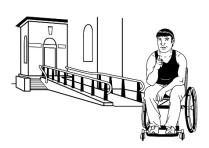
You do not need to answer all of them.



You can **tell us what you think** by using words, ideas, stories, and pictures.



You will then do some **number** questions.



These questions will tell us **about you.** 



These questions will tell the researchers **who answered.** 

We need to know **how similar and different people are** from each other.



You **do not need to answer** all the questions.



You can choose to answer **as many as you like.** 

More information about the questions can be found in on the website: www.flourishingtogether.co.nz



Because this is a new type of study, you will also be able to tell us whether you like this type of survey.

We want to know what **what could be improved** about this survey.

It is your choice if you want to answer the questions in this section.

#### How will I be able to answer?



An online, accessible survey will ask you the questions.



You can **respond in lots of different ways**.



We are making the survey **more accessible,** so you can tell us your story how you want.



We are always **trying different things** to make it better.

Do you have feedback or suggestions?

Then tell us!



You can access the questions in:

- English
- Easy Read
- Te reo Māori [this is coming]
- NZ Sign Language [this is coming]



You can choose to take the survey in the best way for **you to use.** 



You can read the questions in:

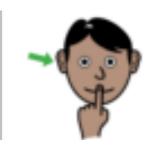
- Easy Read
- Read aloud [choose your speed]
- Video with captioning
- NZ Sign Language [this is coming]



You can answer the survey by:

- Typing text
- Using voice-to-text software from your device (e.g. Dragon)
- Making a voice memo (e.g. record yourself talking)
- **Uploading a file** (e.g. an image, audio file or video file)

Any recordings, photographs or videos you share with us **will only be used by the researchers.** 



They **will not** be made public.



**Please contact us** if these formats will not work for you.

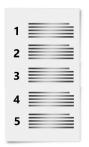


We are happy to try other ways to hear your thoughts and ideas.

#### Are there any risks or costs to me?



There is no cost to you except your time.



We think the survey will take up to **2 hours** if you answered all the questions.

We **do not** expect you to give up this much of your time.



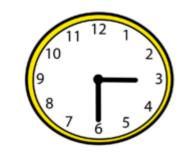
Here are some ways to make it easier for you.



You **do not** need to answer all the questions.



You can **only answer the questions** that are important to you.



If you answer **2-3 story questions**, the survey will take **around 30 minutes.** 



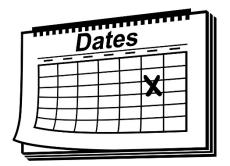
You can also **speak your answers**.



This should make sharing your stories faster and easier.



Your answers can be added **slowly over** time.



The survey will remain open to you for **1 month.** 



You can **go back in** to finish your answers **later.** 



You can **ask others to help** you complete the survey.



We know that talking about your experiences **can be difficult.** 



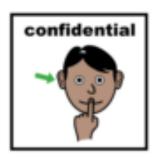
Do you want to talk to someone about **anything** that comes up for you?



Health and Disability Commissioner Te Toihau Hauora, Hauātanga Please ask for support from:

- Family and Friends
- The research team
- Disability advocate from Health and Disability Commission

# What will happen to the information we collect?



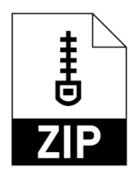
All your answers and information will be private and confidential.



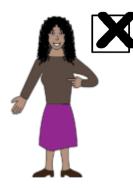
**Only the research team** will be able to see the things you share.



If we use your answers, we will make sure **you will not be identified.** 



Your answers will be downloaded and stored in secure **files.** 



Any personal information that can identify you will be **removed.** 



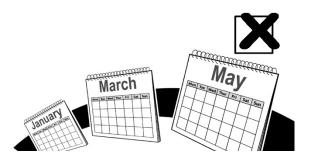
The responses from this study **may be** used in future research.



Therefore, we will also ask for **your consent** for using your responses for future studies.



You can say no to giving this additional consent, but still take part in this study.



This means we will use your responses in this study, but not in any future research.



The information will be **kept for 10 years** and then destroyed.

### How do I agree to take part in the study?



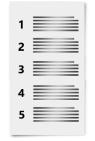
You will be asked to **give your consent** in the online survey.



Go to <a href="https://www.flourishingtogether.co.nz/survey">https://www.flourishingtogether.co.nz/survey</a>

Click on the **red box** to start sharing your thoughts.

#### Who can I talk to about this study?



Do you want to **talk to us** about this study?



Then contact one of the people below on:

- Email
- Phone
- Text
- WhatsApp



Susan Wadsworth Researcher | Disabled Person

Cell: 022 672 0230

Susan.Wadsworth@otago.ac.nz



Jasjot Maggo Researcher

Jasjot.Maggo@otago.ac.nz



Do you have any **questions, concerns or complaints** about this study?



Then contact: **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?



Contact an **independent** health and disability advocate at: **Phone:** 0800 555 050 **Email:** <u>advocacy@hdc.org.nz</u>



This study has been approved by the University of Otago Human Ethics Committee (Health).



Do you have any concerns about the **ethical conduct** of this research?



Then 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 then be informed** of the outcome of your issue.

For the **purposes of research only,** the Easy Read images have been sourced from:



#### **CONSENT FORM**







I **understand** what the study is about.

I have had time to **talk to people** I trust.

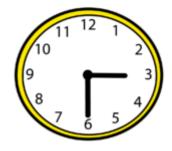
I have had my **questions** answered.

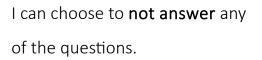
I know it is **my choice** whether I take part in the study.

I know I can **stop** if I want to.

I know that **anything I have answered before I stop** will still be used in the study.

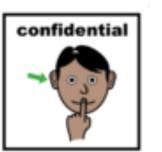


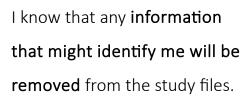




I understand the **time it will take** me.

I understand the **risks** to me.





Any **audio**, **photographic or video materials** I share will not be made public in any way.

I will not appear in any **spoken or written report** of the study.



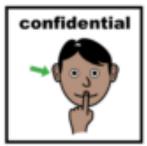
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Signature of participant:

Date:

#### CONSENT FOR FUTURE USE OF DATA:





I consent for the information I provide to be used in **future studies**.

Any **information that might identify me will be removed** before it is used.

Signature of participant:

Date: