



What is important to us in health research



This document is about a research project.

This project is about health research.



It was done by the **National Centre of Excellence in Intellectual Disability Health.**

We call it **the Centre** for short.



For a long time most research about disability was done by people without disabilities.



This meant people without disability made decisions without talking to people with disability.



Research has started to include people with intellectual disability.



But research has not always looked at the things people with intellectual disability said were important to them.



This project was about working together.

The research team included people with intellectual disability.



We wanted to learn what health research is important to people with intellectual disability.



Our team had people who:

- Came from different places



- Had different experiences



We worked well together as a team.



Everyone helped in their own way.



We did the research in two parts.



We interviewed researchers with intellectual disability.



We did an art competition for artists with intellectual disability.

What we found



We found areas of health that were important for people with intellectual disability in this study.



We did not decide which areas are more important than others.



We would need to do more research to decide which areas were most important.

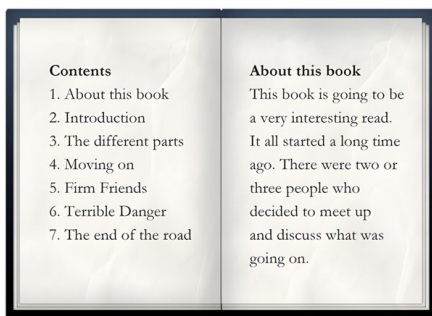
Overarching areas came up in the project.

Overarching means that these areas should be included in all future research projects.



The overarching areas are:

- Lived experience



- Narrative



- Identity



- Person-centred care

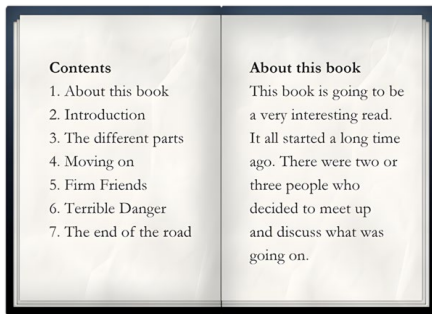
- Autonomy



- Self-determination



Lived Experience means the things you go through in your life.



Narrative means the story you tell about:

- Your life
- What you have been through.



Identity means who you see yourself as.

This is based on what you have gone through.



Person-centred care is about caring for people in a way that respects who they are.



Autonomy means letting people make their own choices.



Self-determination means letting people decide how they want to live their lives.



There is still more to find out.



The other important areas of health research we found are:

- Wellbeing



- Communication and health literacy



- Accessible and inclusive health system practices



- Health promotion and medical conditions



- Art-based research



Wellbeing means mental health is not just about being sick.



It is about being happy to spend time with:

- Family
- Friends
- Nature



It is also about doing things that matter to you.



Communication and Health Literacy means talking in a way that is:

- Clear
- Easy to understand

It is also about listening.



Accessible and Inclusive Health Systems and Practice means that there are things that make it hard for the health system to work well.

It means health workers should be helped to do their jobs better.



Health Promotion and Medical Conditions mean:

- Better health
- Helping people stay health
- Helping people feel good.



It also means learning about health problems.



This will help health workers make people feel better.



Arts-based Research means using art like:

- Drawing
- Music
- Drama
- Other art



We can use art to:

- Find out new things
- Share ideas

What we did well



We had people with intellectual disability help lead:

- The interviews



- The art competition



We showed people with and without disability can work as a team.



We showed that people with intellectual disability know what they want in health research.



The interviews and art competition were good ways for people with intellectual disability to share their:

- Stories
- Ideas

Everyone could share what they thought.



People who do not use speech to communicate could share their ideas as well.



Other ideas from the research



The art competition could be done every year.



The government should listen to what people with intellectual disability say is important to them in health research.



The way we did the research meant people from all over Australia could participate.

It shows other researchers new ways to do research.

Who we talked to



We talked to 16 researchers with intellectual disability.

The artworks



60 artworks by people with intellectual disability were included in the competition.



This is a new way of doing health research in Australia.

It respects everyone.



It includes everyone.



It is important that people with intellectual disability have a voice in health research.