

# CDS

Centre for  
Disability  
Studies

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## ***Being and Keeping Healthy: An Inclusive Research Approach to exploring the experiences of People with Intellectual Disabilities***



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## WHO ARE THE INCLUSIVE RESEARCH NETWORK?

We are a group of co-researchers with intellectual disabilities, their supporters, and university researchers from the Centre for Disability Studies. We do research together. Our motto is “nothing about us, without us!”



## WHAT IS OUR RESEARCH ABOUT?



- We wanted to do research about the right of people with intellectual disabilities regarding health
- We learnt about the UN Convention on the Rights of Persons with Disabilities
- We wanted to find out about how people with intellectual disabilities experienced their rights in their day-to-day life
- We learnt that not a lot of research had been done in this area

## RIGHTS TO HEALTH

We have looked at peoples' rights in the areas of health, housing, education and employment.

- This presentation looks at one of these rights – that of health.
- Article 25 of the Convention says that people with disabilities have the same right to good health and good health care as other people.
- Our research question is “What are the experiences of people with intellectual disability around their rights to good health?”



## HOW WE DID THE RESEARCH

We decided that individual interviews were the best way to get the information we needed.

- So we developed a series of questions on rights around health.
- One co-researcher with intellectual disability and one without conducted the interviews with 24 people with intellectual disability.
- The study was approved by the University of Sydney's Human Research Ethics Committee.



## WHAT WE DISCOVERED

### THE FIVE THEMES FROM THE DATA

1. It's important to have an ally – *somebody on my side*
2. You need to have knowledge – *finding out about health issues*
3. Access – *it's more than just getting into the building*
4. Quality of the doctor – *what makes a good doctor*
5. Concerns in the health care system – *worrying things we see happening*

## HERE'S WHAT SOME PEOPLE SAID ABOUT HEALTH

### IT'S IMPORTANT TO HAVE AN ALLY – SOMEBODY ON MY SIDE

*“Mum reminds me about my appointments ..me, I tend to forget.”*

*“If I get sick, my key workers ring an ambulance or take me to hospital.”*

*“Mum would ring a different doctor if I needed a second opinion.”*



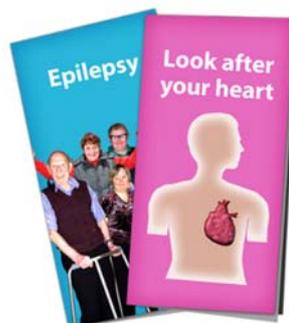
## THE KNOWLEDGE: FINDING OUT ABOUT HEALTH ISSUES

*“I don’t know very much about health ... but hopefully will know more in the future since I have got my computer.”*

*“Seeing specialists: social workers, mental health workers, dermatologist, psychiatrist.”*

*“The internet, computers, Dr Google to find out information or ask my doctor or chemist.”*

*“There ought to be a sort of chain of command for doctors, complaint-wise! (One) that people can understand.”*



## ACCESS TO HEALTH – IT'S MORE THAN JUST GETTING IN THE BUILDING

*“Yeah. It’s difficult to get up all those stairs.”*

*“It’s hard getting public transport out my way...hard to get to my doctor.”*

*“My doctor used to make house calls but that doesn’t happen these days.”*

*“Signage can be a bit confusing at first but you get used to it....”*



## QUALITY OF THE DOCTOR: WHAT MAKES A GOOD DOCTOR?

*“Some doctors come across really rude.”*

*“I’ve seen (my doctor) for a long while now...she’s a good doctor!”*

*“Doctors communicating better with each Other ...I don’t care if they’re specialists or not; they should be able to communicate.”*

*“A good doctor needs to have training and experience.”*

*“They should listen more.”*



## SOME REFLECTIONS ON OUR WORK

### THE LIVED EXPERIENCE OF RIGHTS

Firstly, we have had an affirmation of the value of listening to and learning from the lived experience of people with intellectual disabilities of their experiences of rights around the health care system.

People with intellectual disabilities often give very different perspectives from those of health care professionals, workers, or family members. But this perspective is often not valued.



## THE BROADENING OF THE RESEARCH FAMILY

Secondly, we have learned much about the processes involved in doing inclusive research.

We have experienced a broadening of diversity of the research family. In so doing, we have come to recognise and utilise the different expertises of our group members.



## WORKING WITHIN THE TRADITIONAL RESEARCH SYSTEM

But we also learned that the research system, at least in Australia, is slow to recognise the intricacies of inclusive research. For example, the ethics committee found it difficult to understand people with intellectual disabilities being researchers rather than the subjects of research.

The health and safety requirements were far more demanding for our co-researchers with intellectual disability

Finally, inclusive research takes additional time and resources – issues that are not always acknowledged by funding bodies and research organisations.