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

by

The Centre for Disability Studies Inclusive Research Network

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What is the Centre for Disability Studies Inclusive Research Network?

- We are a group of co-researchers with intellectual disabilities, their supporters and university researchers from CDS, Sydney, New South Wales. We do research together.
- We have been working together since 2010
- Our members have changed over time but we are all still very keen to do research together

“Nothing About Us Without Us”
Some of our Inclusive Research Network Members
Developing Research Skills

• Workshops and monthly meetings over 3 years
• Beginning skills in
  – Developing research questions
  – Ways of gathering information
  – Research ethics
  – Developing interview guides
  – Interviewing skills
  – Analysing the interview information (data)
  – Preparing presentations
What is our research about?

• We wanted to do research about the rights of people with intellectual disability.

• We learned about the UN Convention on the Rights of Persons with Disabilities.

• We were interested to find out what are the everyday experiences of people with intellectual disabilities of the rights covered in the Convention.

• We learned that not a lot of research has 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 found out
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*
It’s important to have an ally – somebody on my side

Mum reminds me about my appointments... 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.”

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....”

It’s hard getting public transport out my way...hard to get to my doctor.
Quality of the doctor: What makes a good doctor?

Some doctors come across really rude.

A good doctor needs to have training and experience.

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.

They should listen more.
Concerns in the Health Care system: Worrying things we see happening

Medication ...To shut them up, do you know what I mean?

Some people have adverse reactions to medications, even though the side effects are supposed to stop that from happening.....

Doctors should treat people with disabilities equally as everyone else

We can teach them what it’s like in hospital
Some Reflections on Our Work

• The lived experience of rights
• The broadening of the research family
• Recognising and valuing the diversity of expertise among the group
• Working within the traditional research system
• Additional time and resources needed in inclusive research efforts
• But an exciting journey lies ahead!
Thank you for your attention
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