

“We have rights, you know”

*An Inclusive Research Approach to Exploring the Views of
People with Intellectual Disability on Their Everyday
Experiences of their Rights in 4 Areas Identified by the
Convention*



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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 learn about the experiences of people with intellectual disability of rights covered in the UN Convention of the Rights of Persons with Disabilities.

One co-researcher with intellectual disability and one without conducted interviews with 24 people with intellectual disability living in Sydney on their experiences of their rights around: *Education, Health, Employment, Housing*.

The study was approved by the University of Sydney's Human Research Ethics Committee.

WHAT THEMES DID WE FIND IN EACH AREA?

HOUSING



- *Choosing where I live and who I live with*
- *Feeling safe*
- *The right support for me*
 - *Managing my money so I can do what I want*
- *Making and keeping relationships that I choose*

HEALTH



- *It's important to have an ally*
- *You need to have knowledge of health issues*
- *Access is important*
- *Qualities of a good doctor*
- *Concerns about the health care*

EDUCATION



- Their dreams and aspirations for their future influence people's learning goals
- Finding out what's available and getting information
- The positive and negative experiences of learning
- What is needed to help people enjoy learning learn

EMPLOYMENT



- Training is the key to employment for people with disabilities
- People with intellectual disability are sometimes bullied at work
- It's important to get a fair go and be treated like everyone else at work
- Sometimes workplaces are not safe and have poor physical access

HOW WE IDENTIFIED THE “BIG IDEAS”...



We put all the themes onto paper and put them up onto the wall, so that housing, education, employment and health were all together in a column.

We then looked for commonalities or big ideas that belonged together.

We kept on re-grouping them until we were happy with the result.

We then gave each big idea a new name.

THE BIG IDEAS

WE IDENTIFIED 3 BIG IDEAS



1. It's not only about having rights, but knowing what your rights are and having them respected
2. It's about inclusion not exclusion
3. There are some things that help – good support, good access and enough money

**“IT’S NOT ONLY ABOUT HAVING RIGHTS,
BUT KNOWING WHAT YOUR RIGHTS ARE
AND HAVING THEM RESPECTED”**



Examples of this aspect include:

Getting a Fair Go

“People don’t always get a fair go, even though they are good workers” (employment)

Having your Choices respected

I looked at the place. They went to so much trouble organising it for me, so I looked at it, but I said “No, I’m not living here.” (housing)

**“IT’S NOT ONLY ABOUT HAVING RIGHTS,
BUT KNOWING WHAT YOUR RIGHTS ARE
AND HAVING THEM RESPECTED”
(CONTINUED)**



Not being discriminated against

“Doctors should treat people with disabilities equally as everyone else” (health)

Understanding from other people

“People not understanding your day-to-day life, your disability... I don’t want to deal with this person. Being negative towards a person with a disability.” (education)

INCLUSION NOT EXCLUSION



Feeling part of the group

“...I met some good people and I formed good friendships with them. I’m thankful for that. It’s just that I felt overlooked by certain.... students.” (education)

Diverse range of relationships

“People have many different kinds of relationships.” (housing)

INCLUSION NOT EXCLUSION (CONTINUED)



Non-judgemental attitudes

“Hopefully future employers will accept people with intellectual and learning disabilities. Want to be treated like any other normal human being. Have to accept and be patient.” (employment)

Respectful relationships

“Some doctors come across really rude.”
(health)

THINGS THAT HELP

GOOD QUALITY SUPPORT



Good quality staff support

“There was a good teachers aide who helped me.” (employment)

“The staff at my house help me practice.”
(education)

“Not anymore. Let’s face it, they’re basically useless.” (housing)

“I’m working with dedicated staff and working in a team ... have the opportunity to teach others and learn from others.” (employment)

GOOD ACCESS



Access to Information

“I’ve done the computer course, but I don’t know about any other courses.” (education)

“You need to have knowledge and to find out about health issues.” (health)

GOOD ACCESS (CONTINUED)



Physical access

“Sometimes workplaces are not accessible.”

(employment)

Access to Transport

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

“Access to skill development opportunities.”

(education)

“I’m learning how to catch the bus.” (housing)

ACCESS TO MONEY

Lack of money makes a good life difficult

“I’m not getting paid enough, I’m a hard worker.” (employment)

“They cost a bit of money, and I don’t have much to spare.....” (education)

“...my pension covers my medication, my dietary things and stuff like that, and so there’s not much money to spend, anyway.” (health)

“It would be good to have the funds to make the house more liveable.” (housing)

WHAT DO OUR FINDINGS TELL US?

Our findings told us lots of things.

Some are:

- People with intellectual disability need to know their rights, and to act on them
- Community attitudes have only changed a little bit since the 1950s
- People with intellectual disability want to feel included and to be treated with respect
- For us, we have come a long way as researchers, but still have a long way to go
- We hope people will be inspired and encouraged by our research