“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

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. We do research together

• We have been working together since 2010

• Our members have changed over time but we are 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 the years

- Beginning skills in
  - Developing research questions
  - Ways of gathering information
  - Research ethics
  - Interviewing and focus group skills
  - Analysing the information (data)
  - Preparing presentations
Our More Recent Work

• We have extended our skills in analysing data to identifying broader themes or “big ideas”

• We have done this in our study on exploring the everyday experiences of people with intellectual disability of their rights listed in the Convention

• Today we will be explaining how we did this
What was 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 from each Area?
The Themes from 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
The Themes from 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
The Themes from 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
The Themes from 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 did we identify 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

• It was a big job that took us all morning to do!
The Big Ideas

We identified 3 big ideas

• It’s not only about having rights, but knowing what your rights are and having them respected

• It’s about inclusion not exclusion

• There are some things that help – good support, good access and enough money
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)
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)

• 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 any more. 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)
Access is more than just getting in the Building

• 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)
Access is more than just getting in the Building

- **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)
More money would help

• 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)

but 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 Was the Main Big Idea that We Found?

Enjoying Life and Not just Surviving!

Some people are just surviving. This is different to enjoying life
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
Thank you for your attention
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