

**We Like to Keep Learning:
An inclusive research approach to exploring the
educational 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 to do with education
- 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

HERE'S WHAT SOME PEOPLE SAID ABOUT HUMAN RIGHTS

ACCESS TO HUMAN RIGHTS

“You have the rights, but you have to know about the rights”

“Some people didn't even know they had rights”

“Some people knew they had rights but were afraid to speak up”

RESPECT OF HUMAN RIGHTS

“Not only about having rights. It’s about knowing what your rights are and having them respected”

“Respect should come from the government, teachers, employers, support staff”

EQUALITY & DISCRIMINATION

“People with disability need to be given a fair go. Not be discriminated against and have their choices listened to and respected”

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

IT'S ABOUT INCLUSION NOT EXCLUSION

“We think everyone should know about our rights (that means people with disability and the community)”

WHAT HELPS PEOPLE WITH DISABILITIES HAVE A GREAT LIFE? HERE'S WHAT SOME PEOPLE SAID...

EMPLOYMENT

“It is hard when you are in a work environment, when you’re the only person with a disability. You’re just trying to do your best and they don’t understand how slow or how much information you need to do your job efficiently”

“We want to try to be ordinary people. We’re not stupid and we have got the right to be at work. Never underestimate a person with disability who knows what they are doing”

ACCESS TO HEALTH SERVICES

“Having a doctor you like and trust”

“You need a support worker who you trust and remembers appointments”

“You have got to have an understanding of what’s going on or have a support worker that knows your background history”

MONEY

“It helps us to have enough money and to do things that help us with support and access”

ACCESS TO EDUCATION

“If I wanted to do a course, I would have to look at support with the notes”

“It is important to have a good education with disability, because it helps you to learn stuff that helps you later in life”

“Access to computers for gaining knowledge”

ACCESS TO TRANSPORTATION

“Getting access to transportation is important o be able to get to places”

SUPPORT

“We think it might be interesting to do the interviews again now that the NDIS have rolled out in NSW”

HOUSING

“Right to Safety”

“I think it is important to make sure no one is going to take advantage of you. You have to ask questions in order to get the answers you need”

NOW LET'S LOOK AT OUR RIGHT TO ACCESS EDUCATION

- 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 education
- Article 24 of the Convention says that people with disabilities have the right to education and the right to realise this without discrimination and on the basis of equal opportunity
- Our research question is **“What are the experiences of people with intellectual disability around their right to education?”**



HOW WE DID OUR RESEARCH ABOUT INTELLECTUAL DISABILITY AND EDUCATION?

- 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 education
- 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

WE LEARN IN DIFFERENT WAYS

- Formal: TAFE, school, online courses, traineeships, industry-based short courses
- Informal: interest groups like radio club, knitting or volunteer work, independent living programs and transition to work programs
- Learn by doing with other people
- Different ways of learning
- Valuing learning experiences – radio club, knitting, volunteer work
- Learning from others and learning with others
- Lifelong learning – learning all the time

A FOUR STAGE FRAMEWORK

Through our research we found 4 key themes arising from the data:

1. GETTING GOING:

This theme is about finding out about learning opportunities. This theme is about knowledge, information and rights.

2. EXPERIENCING & EXPLORING:

This theme is about positive and negative experiences of learning and it's about choice – being able to experience and explore different learning opportunities.

3. STAYING THE COURSE

this theme identifies opportunities and barriers for learning and identifies what is needed to help people continue learning.

4. ASPIRATIONS FOR THE FUTURE

this theme looks at the dreams and aspirations that people have for the future.

GETTING GOING

This theme, Getting Going, is about information and knowing what is available. Having opportunities to do courses was important and this included access to the full range of courses available, not just courses for people with disability.

Some people said that money was a barrier, that some courses were expensive and they didn't have good information about Centrelink assistance or funding.

Some people said that they would like to learn but needed to sort out others things first, such as accommodation or mental health.



WHAT PEOPLE SAID ABOUT GETTING GOING...

Here's what some people said under the category of getting going:

“I haven't done the course yet because the staff have no money, they don't know much about the course...need information.”

“Some courses are very hard for disability people to do.”

“Want to calm down first....in my head.”

“I'm still just trying to figure out how to clean my home properly.”

“I've done the computer course, but I don't know about any other courses.”



EXPERIENCING & EXPLORING

This theme, Experiencing & Exploring, is about the different reasons people have for learning, such as:

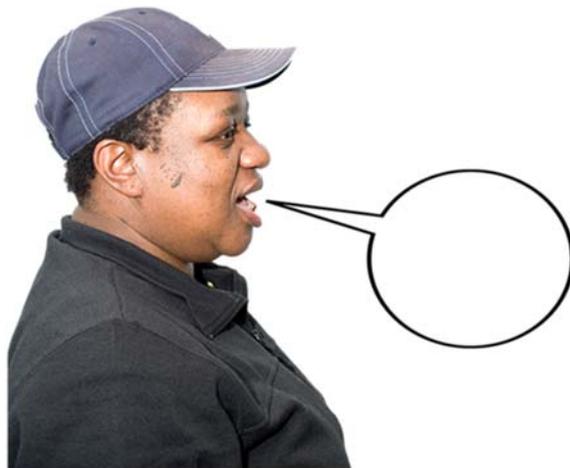
- Career advancement
- To learn a new skill – such as how to use a desktop scanner at home
- To relax by doing a course such as gardening
- To get involved in community work and volunteering
- Wanting to continue learning in an area of previous interest and experience such as working with elderly people
- Wanting to learn more about a subject, such as mental health
- Learning to read and write can lead to a job

WHAT PEOPLE SAID ABOUT EXPERIENCING AND EXPLORING

“Learning is hard. Some courses are very hard for disability people to do. Too fast, can’t keep up.”

“Never been taught. To read and write. Want to learn to. Read and write first.”

“I’ve got a scanner at home. It’s a desktop one, but I’d. Like someone to come in and teach me how to do it.”



STAYING THE COURSE

This theme, *Staying the Course*, is about what is needed to help with learning and to help people to keep on learning.

Our research found that there are some barriers to learning. These include:

- Not being able to take up opportunities because of circumstances
- Money and cost of courses
- Transport – especially at night to attend TAFE
- Episodes of poor health
- Fitting in with classmates
- Negative assumptions from others

WHAT PEOPLE SAID ABOUT STAYING THE COURSE

“At school, I had been in situations of bullying. That was mainly during primary school. And to get over those situations I got involved in sport...”

“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.”

“...At first I might find it nerve-wracking, but to get to know who everyone is, and the teachers, but I find it very...well...scary”

“...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.”

ASPIRATIONS FOR THE FUTURE

Participants in our study had dreams and aspirations for the future. Our research found that participants had a desire to keep on learning and to learn new things. Participants had goals they wanted to achieve. Sometimes the barriers to learning stopped people from achieving their goals.



WHAT PEOPLE SAID ABOUT ASPIRATIONS FOR THE FUTURE

“So I’ve been a teacher’s aide for two and a half years. I’m hoping to combine sports coaching and teacher’s aide work and hopefully one day I’ll be working in a mainstream school doing both jobs.”

“And my goals, well, basically to attempt to create a game with what I know. My knowledge. Gradually build upon it, extend it. Who knows. I might become famous!”

“A radio course...I want one of those jobs.”

“Would really like to do a photography course.”



OUR FINDINGS

- People with a disability have a desire to learn and want to keep learning throughout their lives
- The timing and type of support people receive is critical – especially for accessing courses and staying the course
- It is important to recognise and value the expertise of people with disability
- People with disability have knowledge to share and can educate others, learning from people with disability is important

WHAT WE LEARNT THROUGH BEING INCLUSIVE RESEARCHERS

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, specifically here around the health care system. They often give very different perspective from health care professionals, workers or family members – and a perspective that is often not valued.

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 expertise of our group members.

Team work has taken on a different dimension?

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