

Australia's Disability Strategy Community Attitudes Nested Study

People with intellectual disability

Prepared for the Department of Social Services

Summary Report

Contents

Conten	nts	2
1. Intr	oduction	3
2. Met	thodology	3
2.1.	Co-design	3
2.2.	Focus groups	3
2.3.	Ethical considerations	3
3. Fin	dings	4
3.1.	Education	4
3.2.	Health	4
3.3.	Community services	5
3.4.	Justice System	5
3.5.	Intellectual disability and employment	6
3.6.	Changing attitudes	7
4. Cor	nclusion	8

1. Introduction

JFA Purple Orange were engaged by the Australian National University (ANU) to conduct a nested study as part of Australia's Disability Strategy Survey to investigate how people with intellectual disability experience attitudes towards disability in various sectors such as education, health, justice and community services and in employment settings.

This study comprised six focus groups with people with intellectual disability. Each focus group explored the attitudes experienced in relation to a specific sector.

The overall aim of the nested study was to explore how attitudes held by others can affect the wellbeing and experiences of people with intellectual disability in different parts of their life.

2. Methodology

2.1. Co-design

This nested study was informed by co-design. The co-design group had representation from three people with intellectual disability and three supporters with expertise in the field of intellectual disability.

The co design group provided advice on:

- recruitment strategies, including the scope of the research
- the format and set up of focus group sessions
- accessibility considerations in the focus group.

2.2. Focus groups

In total, there were 24 participants across 6 focus groups. All focus group participants live with intellectual disability and were aged over 18. They came from every state except Tasmania. Each group focused on attitudes experienced with one of the four target sectors, education, health, justice and community services and two groups focussed on experience with and barriers to employment.

The focus groups aimed to find out about both positive and negative experiences with workers in the target sectors, including how workers' attitudes affected them, what was good or bad about it, what could have been better and what it feels like to be respected and treated like an adult.

2.3. Ethical considerations

The ANU Centre for Social Research and Methods obtained ethics approval following a full review by the ANU Human Research Ethics Committee under the National Statement on Ethical Conduct in Human Research (Protocol 2022/467, 25 November 2022). All participants provided informed consent prior to taking part in the focus groups.

Due to the sensitive nature of research questions, all participants were asked if they would like a follow up phone call after participating in the focus group just to check they were okay

and to see if they had any further comments. Participants were also provided information about where to seek support if needed following the focus group.

3. Findings

3.1. Education

Participants talked about their positive experiences at school including being treated with respect, listened to, treated the same as other students and supported well with areas where they needed assistance.

They particularly valued support workers and teachers who recognised that someone's disability affected performance in some areas, but need not be a barrier to other further education in other areas. They noted that when they explained their disability educators listened and gave them helpful advice.

Some participants shared stories of successfully completing TAFE courses in hair, make-up and business and said they found TAFE to be a welcoming environment which helped build their confidence.

The most significant negative experiences were low expectations. Many felt that low levels of expectations in education settings limited their opportunities to learn things that are interesting or relevant. These low expectations among teachers reinforced and deepened entrenched negative perceptions of disability. Some also reported these low expectations affecting their sense of worth and value and their expectations of themselves.

Most participants reported positive attitudes among their peers at school and emphasised how important friends were in protecting them and preventing bullying. Participants also mentioned how important it was for them to participate in areas where they had particular skills and how this helped to build friendships. Winning against peers helped to make friends and change attitudes too. Participants defined positive attitudes as 'being treated like everyone else' or as just one of the group. They felt included and weren't singled out or made to feel different because of their disability.

However, participants all shared experiences of bullying, particularly in high school. Bullying often took the form of name calling or making upsetting comments about their disability. Sometimes being the only person (identifiable) in the school was a lonely experience and seemed to increase the feeling of being "the odd one out" or excluded. Some people with intellectual disability do not outwardly present or identify as having a disability. This meant that while peers observed differences, they didn't understand these differences were due to disability. Instead people saw differences as 'odd' or 'weird', reinforcing the feeling of not fitting in with friendship groups.

3.2. Health

Participants described mixed experiences in healthcare. They tended to draw on experiences of going to the GP or going to the hospital (for scans or surgeries). It was important to note that many of these participants highlighted barriers with accessing healthcare because of the costs associated with bulk billing or issues with NDIS funding allied health services, an issue that is not only specific to 'attitudes'.

Participants were mostly positive about their experiences in healthcare. They described positive interactions with doctors, nurses or health professionals in terms of 'they listened', 'they treat me well', 'they answer my questions', 'they take the time to get to know me' and 'they draw diagrams to show me what's wrong'. Participants also said that having a support person with them during health appointments was useful, particularly if information was dense or complicated.

Participants all highlighted that when doctors were familiar and knew them well, their experiences tended to be much more positive, as their doctors knew more about their history, what their needs were and how to best support them. It was clear that familiarity and historical contact helped people with intellectual disability to feel safe, respected and well-supported.

Negative attitudes and behaviours were also common in health settings, particularly for participants with 'invisible' intellectual disability, such as difficulties reading and writing. Experiences of taking a support person were mixed, with some finding it helpful, especially if the information provided was difficult to understand, while others reported the worker talking to the support person rather than the person with disability. This suggests that doctors may sometimes see the support person rather than the person with disability as the 'authority'. When this happens, the patient can feel like that they are not in the room, or are invisible. Participants also reported that going to a new health service or specialist was often negative as the worker often doesn't understand the disability or its impact on the patient.

3.3. Community services

Participants described many positive attitudes from their support workers. Participants were clear that a positive attitude towards them was also one of mutual respect and reciprocity. They saw it as a two-way street, where support workers took the time to get to know each person and supported them to do things they wanted to do.

In terms of experiencing negative attitudes, participants talked about the differing needs of individuals and how community service professionals sometimes disregard this and make assumptions based on their previous experiences of disability. They also noted that workers in the sector often misunderstand communication or the use of gestures to get someone's attention. Communication break-down and misinterpretation of behaviour stemmed from lack of understanding and judgment, which significantly hampered building positive regard.

These examples are underscored by attitudes around 'behaviours of concern' that tend to follow people with intellectual disability in deeply negative and harmful ways. Participants said that many professionals who work in community service sectors do not have lived experience of disability and, in turn, participants felt that these professionals did not understand, listen to or accept who they are.

3.4. Justice System

Experiences with the justice system were quite varied, such as being a bystander, providing information to police, reporting theft to police, through to a more serious crime of sexual assault. Participants also reported dealing with restraining orders against them and guardianship issues. The diversity of these experiences reflects the broader literature

highlighting that people with intellectual disability are over-represented in all aspects of criminal and civil court systems, both as perpetrators and as victims.

Participants struggled to highlight any examples where people working in the justice system had treated them in a positive way with respect. Experiences of the justice system are distressing and stressful for most people and this distress is compounded by intellectual disability. This can lead to communication breakdown and negative interactions with police. Particularly when someone has an invisible disability, this can make it harder to identify why someone may be acting in an unexpected way or may not be following instructions.

Participants talked about workers in the justice system making assumptions about them rather than taking time to understand them. In one situation, a participant said he had reported sexual abuse. However, he was not believed and did not see police act on his report. Participants also described how security staff and police mistook an unbalanced walk and slurred speech associated with someone's disability as drunkenness and as a result, removed the person from the venue.

Participants reported dealing with issues of domestic violence, homelessness and other issues. These experiences further compound negative experiences in the justice system and may also deepen distrust of police, lawyers and court processes. These social issues of disadvantage may further compound stigma and lack of support from police making it difficult to determine whether negative attitudes stemmed directly from attitudes about disability.

3.5. Intellectual disability and employment

Two focus groups were held in relation to attitudes in employment. Participants worked in a range of jobs. Most worked in supported employment situations such as wood working, in the kitchens and in aged care and laundry work.

Participants were mostly positive about their managers and supervisors and were able to describe what made a workplace good for them. They described instances where they had positive feedback from people around them about their contributions to the workplace. Participants consistently defined a positive attitude in the workplace as:

- having someone who understands disability and ways that people can learn and work (such as writing instructions down, or showing someone how a task is done)
- providing positive feedback about their contributions to the work
- checking in to see how things are going and ask if help is needed.

For participants, a good workplace meant:

- They were helping with the work and making people happy.
- They were learning new skills and working on different tasks.
- There were people who were friendly and good communicators.
- Others in the workplace were happy to help.
- They were being treated with respect.
- They were able to take a support person to meetings for extra help

- They had opportunities to develop skills.
- There was flexibility to choose their tasks and jobs.

However, participants were also able to describe workplaces where people's attitudes to their disability had a negative impact on them. They described workplaces where they had made mistakes or had misunderstood the task at hand and were not supported by managers or supervisors. Instead, they were fired or lost their jobs. In one instance a participant lost their job due to a personal accident and another, who worked in laundry, described how they were pushed out of the workplace and their request to bring a support worker to a meeting was denied.

In general terms, participants said that employers did not understand how disability affected them or what strategies could be put in place to support them in the workplace. There were general themes among all the examples given of not feeling accepted or welcome in mainstream employment, which pushed participants towards supported employment. Low expectations in the workplace were also compounded by experiences of low expectations among family members, who wanted to avoid risk and protect participants from harm by lowering their expectations for work.

3.6. Changing attitudes

All participants highlighted the importance of listening to people with disability. Participants wanted people with disability to be given the freedom to decide and test their own limits and skills. Participants wanted decision-makers in the target sectors and in workplaces to take into account the way people with disability learn and enable multiple ways of learning as part of their inclusion strategies. This finding was resounding across all focus groups.

Participants also talked about the importance of challenging low expectations, particularly in education and employment settings. Participants talked about the negative impact of low expectations and how this reinforced and deepened entrenched negative perceptions of disability. Workers in all sectors need to hold high expectations for people with intellectual disability and see and acknowledge their strengths and contributions.

Participants in all focus groups said that training and education about disability helped people to change their attitudes. Further, participants highlighted the importance of training and education led by people with intellectual disability.

4. Conclusion

The findings indicate that participants with intellectual disability contend with attitudinal barriers across all the target sectors and in employment. These include:

- not taking the time to get to know people with intellectual disability
- low expectations of capacity, which in turn limit opportunities for meaningful employment or education
- dismissal of intellectual disability and not making information or communication easier to understand
- stigma and stereotypes which are further compounded by stigma associated with socio-economic issues such as alcohol, homelessness and domestic violence or crime.

Participants felt that there is an attitude or belief that people with intellectual disability are vulnerable and need protection. Participants found this frustrating. Instead, they wanted to be listened to and supported to make their own decisions about how they participate and engage in all aspects of community.

Participants also talked about experiences of positive attitudes towards them that included being treated with respect, listened to, talked to, and valued for their contributions. Many of these positive experiences came about when people took the time to get to know and understand them. Often these positive attitudes played a key role in improving outcomes for the participants in various areas of life and even played a role in the person feeling safe in the environment.

Many participants emphasised the importance of getting to know people with intellectual disability over time, learning more about who they are, their history and background and what their strengths and skills are. They wanted everyone in community to educate themselves and undertake training and education designed and led by people with intellectual disability.





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