



Australia's Disability Strategy Community Attitudes Nested Study

People with intellectual disability

Prepared for the Department of Social Services

Acknowledgements

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Preface

JFA Purple Orange is an independent, social-profit organisation that undertakes systemic policy analysis and advocacy across a range of issues affecting people with disability and their families.

Our work is characterised by co-design and co-production, and includes hosting a number of initiatives led by people with disability. Much of our work involves connecting people with disability to good information and to each other. We work extensively in multi-stakeholder consultation and collaborate to develop policy and practice that helps ensure people with disability are welcomed as valued members of the mainstream community.

Our work is informed by the Model of Citizenship Support. This model, developed by our agency, provides a framework for advancing and maintaining life chances so that each person can live a good, valued life of Citizenship. The Model asserts that our life chances comprise four different, interrelated, types of assets we can call upon, termed the Four Capitals. These are: Personal Capital (how people see themselves); Knowledge Capital (what the person knows and learns); Material Capital (money and the tangible things in our lives); and Social Capital (having people in our lives whom we know and know us). Citizenship describes a situation where a person is an active and valued member of their local community. Their lifestyle is informed by personally defined choices, and they can grow through their involvement in meaningful activities and by their participation in a network of relationships characterised by acceptance, belonging and love. You can find out more about this model on our website, purpleorange.org.au.

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

This nested study was informed by co-design. The co-design group provided advice on the focus group methodology and targeted recruitment approaches in order to engage people with intellectual disability.

2.1. Co-design group

A co-design group was established at the beginning of the project to guide the consultation process. This 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.

The advice from the co-design group informed the design of the study in several ways, including:

- ensuring the focus groups had national coverage
- offering online and face-to-face options for participation
- ensuring that online focus groups were kept small, so that everyone can be seen on the screen
- rewording of questions to ensure they can be easily understood.

2.2 Research participants

In total, there were 24 participants across 6 focus groups. Focus group participants were recruited through Purple Orange's networks with the assistance of Inclusion Australia and Down Syndrome Australia. Focus group participants were from South Australia (SA), Queensland (QLD), New South Wales (NSW), Victoria (VIC) and Western Australia (WA). All focus group participants live with intellectual disability and were aged over 18. Participants were recruited to the following groups:

- Education
- Health
- Community services
- Justice system
- Employment and workplace settings

2.3 Focus groups

The focus groups were facilitated by staff from Purple Orange who have extensive experience in working with people with intellectual disability, as well as other forms of disability.

In total, there were six focus groups. Each focus group concentrated on attitudes in one of the targeted sectors: education, health, community services and justice. There were two focus groups run in relation to attitudes and behaviours experienced in employment settings. This was done to enable participants with interest in this area across multiple time zones.

At the time of each focus group, the Easy English Participant Information Sheet was supplied and explained in full. This information sheet included details about the study and also explained the rights of the participants. Consent to participate was obtained from all participants.

Participants were informed that the information they provide may be included in a report that is made public, but that they would not be identified in any way.

Discussion questions were developed to guide the conversation. However, these questions were adjusted depending on the group and the direction of the conversation. The main questions put to participants were:

- Can you tell us about a time when you experienced positive attitudes at a visit to the doctor [or worker in one of the other target sectors]?
 - What did they do? (How did they speak to you? What was their role?)
 - How did this impact you (How did this make you feel? Did it change anything you did)?

- Further prompts around different attitudes of different staff, what it means to feel respected, what it looks like to be treated like an adult etc.
- Can you tell us about a time when you experienced negative attitudes at a visit to the doctor [or worker in one of the other target sectors]?
 - What did they do? (How did they speak to you? What was their role?)
 - How did this impact on you (How did this make you feel? Did it change anything you did)?
 - What could be changed/what could have been better? (What would a good visit to the doctor look like?)
 - Further prompts around different attitudes of different staff, what it means to feel respected, what it looks like to be treated like an adult?

All focus groups participants were provided a \$60 gift voucher to thank them for participating.

2.4 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. The research team provided all participants with accessible information about how the focus groups would be conducted and provided them with background information prior to the focus groups. The online focus groups were recorded after obtaining consent from all participants.

All data captured during focus group sessions was stored securely in a password-protected electronic file within the JFA Purple Orange office. Data was stored in a de-identified and confidential format, with only the research team having access to the data.

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.

Follow-up calls were attempted with all participants. One participant indicated in the follow-up call that they found some of the content discussed somewhat distressing, but that they were feeling fine again the next day. They were offered further information about referrals and supports, however they indicated that this was not necessary.

2.5 Limitations

While the purpose of this research was not to provide a full representative analysis of the views of people with intellectual disability in Australia, it is worth noting some specific limitations in relation to the findings.

- As detailed above, focus group participants were from SA, WA & NSW, VIC and QLD. There were no participants from the Northern Territory (NT) or Tasmania. Further, participants from SA were overrepresented.
- The total number of participants for each focus group was small, varying between 3 and 5 participants per focus group.
- It was particularly challenging to recruit participants to the focus group focusing on 'justice system and legal professionals'. This is possibly due to the sensitive nature of this topic as people were unlikely to comment on attitudes in the justice system unless they had some interaction with the justice system.

3 Findings

This section reports the findings across five sectors:

1. Education
2. Health
3. Community services
4. Justice system
5. Employment and workplace settings

It should be noted that in some focus groups, participants recalled examples that were relevant to other sectors. For example, a participant in the community services focus group also raised examples relevant to health sector. Where this is the case, the findings were presented in the most relevant 'sector' section.

While all focus groups were each asked 'how do we improve attitudes towards people with intellectual disability' the answer was resoundingly the same across all focus groups and therefore this section is presented as a concluding 'call to action' at the end of this report in an effort not to duplicate information.

3.1 Attitudes about disability in education

The first focus group focused on attitudes in education settings. This focus group consisted of four people with intellectual disability (two from NSW, one from SA and one from QLD, all living in metropolitan areas).

3.1.1 Attitudes among educators and education leadership

Participants talked about mixed experiences of teachers, principals and other aspects of both primary and high school, as well as their experiences of TAFE and university. Participants described times when they felt well supported, listened to and respected, as well as times when negative attitudes wore down their resilience and impacted their sense of worth.

3.1.1.1 Positive attitudes of educators

Participants tended to talk about their experiences in primary and high school and described experiences of being:

- treated with respect
- listened to
- treated the same
- talked to
- supported well with areas where they needed assistance.

There was a comment made by one participant that because she presented ‘typically’ (had an invisible disability) this helped to control negative attitudes.

“The students, the parents, didn't know anything, I was just same as everyone else and I was treated respectfully. If anyone asked, then we just said x has a couple of challenges. And that was it, okay. Move on.”

Most people said they had school support officers in primary and high school to help with learning and for the most part, felt that these people had positive attitudes towards them.

One participant described the positive experiences she had during career advice and planning session where teachers recognized how her intellectual disability impacted on scores in some topics, but helped her to see that this would not stop her from going on to university or further study.

Participants also talked about their experiences in higher education. They noted that when they explained their disability, their educators listened and helped point them in the right direction as needed:

“I had good teachers there and they understood my disability and stuff. And I explained what I needed help with and they put me in the right direction, so I had a positive experience.”

This experience was shared by others who had completed several TAFE courses in hair, make-up, IT and business. Participants shared that these experiences were enjoyable and found TAFE to be a welcoming environment. Being able to undertake a course in an area of interest helped build confidence and reinforce positive attitudes towards them.

3.1.1.2 Negative experiences

Participants all talked about the low expectations placed on them by teachers and others in the education sector. This limited opportunities for students to learn things that were interesting or relevant. There were consistent themes among the participants about the level of low expectation among teachers which reinforced and deepened entrenched negative perceptions of disability. Participants described the teachers in the disability unit being worse than teachers outside the disability unit as they tended to focus on teaching life skills which were often too basic.

"I struggled at high school myself, one of my teachers [would teach me to go] up to a café and buy a cake and coffee. What's the point of going, what's the learning outcome? Just learning how to pay for things..."

One participant said that teachers were often risk averse and protective of students with disability and prevented them from doing topics that interested and motivated them because they felt that it was 'too hard'.

"Their basic level of learning was far too basic, it didn't challenge anyone. It didn't challenge anyone in the subjects that they wanted to do. Or even had to do. This is where that dignity of risk comes from that top level."

These low expectations from educators affected participants' sense of worth and value:

"You can't expect students to respect you whatsoever if the broader community of the principals, teachers, support staff and even the parents to a degree... they all have to be on the same level, well informed and educated. Language hurts just as much as sticks and

stones... They (educators) have low expectations for people with disability of what they can achieve which is stupid, it's really hypocritical and it's damaging and that's not just high school that's TAFE, that's university, and until that bit of paper changes for a qualification for the access for people with disability, nothing is going to change. I know that was big but it's close to my heart."

One participant said that she, in turn, had lower expectations for herself and that she didn't want to try to improve those basic life-skills. Participants talked about the dignity of risk that comes with choosing topics that interested and motivated them to learn. They said that rather than giving them the support they needed, they were discouraged and were told that it was too hard. For example, one participant wanted to enrol in classes that she had an interest in, such as business studies. However, the special education teacher was discouraging and negative, telling them that they "can't do this topic, it's too hard for you". Despite this advice, the participant went on to TAFE and completed a business course. These negative low expectations from teachers and the broader community impact significantly and shape self-perceptions of worth and capability.

"...it's the little things, 'you can't do that, I'll do it for you'. I have been [told] repeatedly, every day of every part of your life...They add-up, they make bigger problems and I've got a lot of challenges in that mental health space because of it."

3.1.2 Attitudes among other students and peers

Participants also highlighted the importance of making friends and finding people who shared similar interests.

3.1.2.1 Positive attitudes among peers

Most participants said that they had positive experiences of making friends at school and emphasised how important these friends were in protecting and preventing bullying. When there were negative interactions, these friends stepped in and spoke up to support them.

"A mix (of positive and negative experiences) between my friends and other friends, but my friends told them off."

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. One participant described a tension in disclosing her disability to friends and mentioned that while she had bonded with her peers in her favourite topics where she excelled, they did not know she had difficulty in other topics due to intellectual disability.

"I was a very arts based student and my friends - they didn't know [I had a learning disability] at all which presented its own problems... I was part of everything, everyone knew me, everyone was very kind, supportive, we had a bit of a hang, us arts students would hang out in the art room and every lunch doing our art projects."

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.

3.1.2.2 Negative attitudes among peers

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.

"I used to go to high school in x and they have been mean to me, calling me names. They're pointing at me and laughing at me... one horrible word they said to me, and I feel really upset about it. They called me a retard and it made me feel like, true, because I don't have any friends and don't have no one to talk to. But now I realised that I've got a partner, that I can talk to now. So he made me feel more happier and I feel happy that I got better friends than them."

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.

"In high school I had a terrible experience because the school doesn't know that I had an extra chromosome... I was the only one in the school who has Down Syndrome and also an intellectual disability and I was the odd one out because I didn't fit in. I didn't fit in to the friendship groups, I was bullied."

3.2 Attitudes about disability in health

This focus group was based in person in Adelaide and consisted of five participants, all from metropolitan SA. 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'.

3.2.1 Positive attitudes in health

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".

"I will start with hospitals, my two experiences there have been good, they explained everything. Treat me well. GP answers my questions, what I'm doing, how I'm feeling."

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.

"I've got a good GP, go to the one that knows your family..."

These examples indicate that doctors and medical professionals were more likely to develop a positive rapport and be at ease with patients with disability over time as they learned more about the individual, their history and their needs.

3.2.2 Negative attitudes in health

Some participants highlighted that when intellectual disability is invisible, it is harder to get the right support from a GP, as they may not have enough understanding of how intellectual disability affects reading and writing.

"I think they misunderstand, because I look normal, I have a reading and writing problem, can't tell, I speak normal, everything I think when it comes down to the understanding of my interpretation of what it is and their interpretation, can be two different things and misunderstanding in some ways."

One participant said that the doctor's attitude changed when they brought along a support person with them:

"I think as far as if you go with a worker or that, it does change the way the doctor looks at you and talks to you, they will talk more to the person, the carer, or the family member, because they'll listen to what they've got to say, and not what you have to say."

This suggests that doctors may sometimes see the support person rather than the person with disability as the 'authority'. Participants also said that often the information

that doctors or health professionals provided was too difficult to understand, so participants had to bring a support person with them to help explain.

“I won't go on my own because a lot of medical staff, things they talk to you about, I can't, you need someone to explain in the way you can understand.”

Participants also talked about the difference in attitudes between doctors they have known for a long time versus new doctors and specialists who may not feel comfortable or at ease with treating a patient who has intellectual disability.

“When you go to someone new, maybe specialist, doesn't know you, they talk to other people not to you... Doesn't make you in the room, [it makes you] invisible.”

New doctors and health specialists may be unsure of how to communicate or talk to individuals with disability. New doctors may also be at a disadvantage as they do not know the medical history or background, which can make the interaction more complicated both for the patient and for the doctors.

3.3 Attitudes about disability in community services

There were four participants in the focus group about attitudes of people working in community services: one from rural VIC, two from metropolitan NSW and one from metropolitan SA. Participants highlighted a range of examples of seeking support from advocacy organisations, disability services and support workers.

3.3.1 Positive attitudes

Participants described many positive attitudes from their support workers. They described support workers as “loveable”, “huggable” and “they talk to me like a friend”. Moments of reciprocity were highly valued, for example taking it in turns to shout each other a coffee. Participants highlighted several examples where support workers were warm, giving and “made me feel good.”

“I have people, they know what I like in my house. I have a support worker, I have people from multi-cultural backgrounds and they give me a hug, put their arms around me and they know what makes me feel good, they listen, you feel valued, have a sense of belonging, and have the basic rights met, like everybody else. Without feeling excluded and cut off from the community.”

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.

3.3.2 Negative attitudes

Participants talked about the differing needs of individuals and how community service professionals disregard this and make assumptions based on their previous experiences of disability.

“I wish they would consider us because even though we've got disabilities, because some disabilities are different to other people's disabilities. They need to consider how we want to be treated and the way how they get treated. Like it's important because if we want to be nice and kind to people, why they can't do the same thing.”

Some participants also highlighted how service professionals misunderstand communication.

“I had an advocacy organisation treat me poorly, they don't understand the way I communicate and my intellectual disability, and that my characteristics are just part of the disability what they think could be a risk or what they think I'm doing is not what I think I'm doing... I tried to put my hand out ... just get their attention and communicate, but that operations manager thinks that I'm harming her when I'm not trying to harm or hit them, I'm trying to get their attention to tell them that I'm talking to them.”

Communication break-down and misinterpretation of behaviour stemmed from lack of understanding and judgment. This significantly impacted on 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 or accept who they are.

"The majority of people in there that are employed, and have not got a lived experience of disability and recently I've struggled for the past eight months to find a peer support program, discussion group, like to what we are all doing today and I have found nothing at all in New South Wales, I have to join groups in other states or overseas just to be able to have a sense of belonging, contribution, valued, heard, accepted and to have the basic rights met through the national standards for disability."

3.4 Attitudes towards disability in the justice system

The focus group centred on experiences of attitudes in the justice system consisted of four participants from metropolitan WA. Participants drew on a range of mixed experiences in the justice system, such as being a bystander, providing information to police, reporting theft to police, through to a more serious crime of sexual assault. For one participant, the experience of the court system was to do with a restraining order taken out against him. In another instance the court system was involved in relation to guardianship orders. The diversity of these experiences is reflective of 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. Given that interactions with police, lawyers and other aspects of the court system are usually in response to problems or crime, it's not surprising that positive experiences were scarce. Experiences of the justice system are distressing and stressful for most people and these experiences are compounded by intellectual disability. For example, the issue of dealing with car registration may seem a simple issue to fix for someone without disability. However for one participant with intellectual disability, the processes were

difficult to understand, which led to a great deal of distress and meant that he was fined heavily.

3.4.1 Positive attitudes

Participants struggled to highlight any examples where people working in the justice system had treated them in a positive way with respect. However, they did identify how they would like to be treated. Participants said that justice system personnel shouldn't make assumptions about why a person is responding in a certain way and not assume that it is always because of drugs or alcohol. Instead, they should take the time to understand and get to know each individual person and get the full story before making judgments.

"They shouldn't assume. They should get more, like, understanding rather than thrown in the deep end, assume that they're drunk and want to kick them out, they should really get the whole story, not just stigmatise him. They need the full story."

Participants also felt that it was important to listen to participants and respond to reports or issues that were raised in a timely way instead of ignoring or leaving the situation unresolved.

"Actively listen to them is the first thing and then follow-up on whatever is happening to them as well. Not just leave them out to dry. I think that's the very most important step, to actively listen, not judge them and make sure to follow-up, and hopefully whatever their situation is can be solved."

3.4.2 Negative attitudes

Participants highlighted a range of interactions with police. The nature of intellectual disability means that there are barriers to processing information and this is made more difficult when under stress. 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.

“With police a couple of times where I've got threatened and I've done nothing. I even got assaulted once.”

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.

“I was living on the streets and one or two people were very nasty. I was just picked on for no reason. I don't like that. The police are not worth having because they're weak and they don't do anything. When you have an issue like your car got stolen..., they don't care.”

In another situation, a participant said he had reported sexual abuse. However, he was not believed and did not see police act on his report.

“When I was sexually abused. I don't bring this up very often, but I went to the police. I got assaulted once and the police did absolutely nothing.”

Participants also described how security staff and police mistook an unbalanced walk and slurred speech associated with someone's disability as drunk behaviour and as a result, removed the person from the venue.

“I have a friend I went in with and they kicked him out. They thought he was drunk. I said no. They didn't believe me. They kicked him out. What the hell. A lot of people has to understand that people have disabilities.

They don't understand that people deal in different ways. They think it's not normal."

One participant said that people often assume only people in wheelchairs have a disability. When people have an invisible disability, such as an intellectual disability, this was often dismissed or not taken into account.

As participants moved through the court system in an attempt to resolve issues, they found that the court processes were difficult to understand and again compounded when under stress. This made it difficult to understand the decisions that were being made and resulted in a frustrating experience.

"It was just nasty. There was one judge who was nasty and I didn't understand what was going on... It took me to the last stage for the three judges to get me off. It's terrible. It was a lot of wasted time just to get off. It should be simple ... but it's not."

3.5 Intellectual disability and employment

Two focus groups were held in relation to attitudes and behaviours in employment settings - three participated in the morning session (two from metropolitan NSW, one from metropolitan WA) and four participated in the afternoon focus group (one from rural SA, two from metropolitan SA and one from metropolitan WA).

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. One participant had done courses in auto mechanics and was applying in tyre and car shops but had not found a job outside supported employment at the time of the focus groups.

3.5.1 Positive attitudes

Participants were mostly positive about their managers and supervisors. They described instances where they had positive feedback from people around them about their contributions to the workplace.

"I felt really good there, I got to try lots of different things and different areas. And then now at my current job there has been a few good things where people have been happy to let me do a job and they're like 'she's always happy to help' and stuff."

Participants consistently defined a positive attitude 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.

3.5.2 Negative attitudes

Participants 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.

"Someone couldn't wait to do in, didn't give a chance to stop cleaning the car to go and talk to anybody about the mistake... they couldn't understand and fired me then and there."

Another participant 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.

“They wanted me out the door really, they tried to make it hard as possible for me. They cut my hours, they made more work, plus what I normally do, which was hard, also I got treated and spoken to in a not so good way by the managers because of who I am and my disability. They know I was doing a good job. They just wanted to make my life hard at the end and they weren't very pleasant to work with because they didn't want to help me in training or they spoke to me, aggressively, and didn't want my support workers to go to meetings, as well. I had a right to have someone there.”

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. One participant said that they felt “ganged up on” in the workplace because of their disability.

There were general themes among all the examples given of not feeling accepted or welcome in mainstream employment, which pushed participants towards supported employment.

“Because mainstream, they don't want someone with disability around while they're selling cars that's how I see it.”

Low expectations in the workplace were also compounded for participants by experiences of low expectations among family members who wanted to avoid risk and protect participants from harm by lowering their expectations for work.

“I do have really good family, I have really supportive family. But sometimes they make judgments on me and making things not so easy for me. They say you can't do things like that because it's too hard for you. Or I can't get my own job, I can't have my own baby. That made me feel sad that I can't have a baby because with my disability, but I can't change that somehow.”

3.6 What does it take to change 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 all sectors 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 group sectors.

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 attitude. Further, participants highlighted the importance of training and education led by people with intellectual disability.

“I think we should have disability awareness training for all support workers...They should have people like us doing the training and peer mentoring as well.”

When asked how we could change attitudes for the better, participants said “just listen to us” and saw this as the first step to disrupting negative attitudes and stereotypes.

Participants felt that it was about respecting people with intellectual disability and showing dignity and value at an individual and interpersonal level.

Participants said that developing an inclusive environment benefitted everyone, not just people with intellectual disability.

“It's important to understand that people with the lived experience of down syndrome or other intellectual disabilities, they know how much they can do. And it's only through listening to that, it's important to recognise that, and they have to recognise that we are all unique.”

Everyone is unique in representation. No one is perfect. And the education system it's set up so backwards in the fact there's so much leading research on education, around the world, of how 90 percent of the population are visual learners. Intellectual disability or not. So let's utilise that, put that into TAFE into university and high school, actively get people engaged with, not sure you've heard of the term meta learning, the art of learning how to learn, that's ground breaking information on education, training, why isn't that being adapted into the education system."

While the above quote was specific to education, the same applies in terms of better understanding the diversity of ways people communicate and learn and process information. This was heard consistently across all focus groups in health, education, justice and community services as well as those discussing employment

4 Conclusion

The findings indicate that participants with intellectual disability contend with attitudinal barriers across all sectors. Participants reported similar issues of professionals working in all of the sectors, including:

- 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.

In many of the examples, it was clear that participants were dealing with micro aggressions, discrimination and stigma, not only from paid professionals working in such sectors, but also from bystanders, peers, colleagues and others who were part of the context.

Participants wanted to have opportunities to take risks, such as enrolling in a business course, despite being told it was too hard for them. It was clear that many participants had experiences of professionals stepping in to 'help' by trying to lower expectations.

Underscoring this is an attitude and 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. For example, having a teacher believe that their disability didn't mean they couldn't go to university, impacted the choices an individual made; or having a doctor that listened to and respected the person meant that they felt safe in that 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.

JFA Purple Orange would like to thank ANU for the opportunity to undertake this consultation in the disability community. Please get in touch if you have any questions.

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