Inclusion Australia

Stakeholder engagement analysis

People with an intellectual disability and their families' experiences in employment

1 March 2023

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Introduction

In late 2022 and early 2023, Inclusion Australia undertook a substantial policy project with people with an intellectual disability and families, exploring barriers and opportunities to inclusive employment. We received funding contributions to do this work from philanthropy and People with Disability Australia.

As part of this project, we conducted extensive stakeholder engagement over several months including a project advisory group, interviews, surveys, and individual consultation. We provided a detailed submission the Disability Royal Commission, entitled *Equal Pay, Equal Rights: Disability Royal Commission submission on inclusive employment for people with an intellectual disability*, on 23 December 2023.

Our stakeholder work was a key element of the submission and informed the recommendations and analysis within it, however we did not have time to write up our full analysis before the Commission's deadline for submissions closed. The key recommendations in the *Equal Pay, Equal Rights* submission directly respond to what people with an intellectual disability and their families and supporters say about how to make employment more inclusive. We believe that this peer approach to stakeholder engagement is fundamental for developing solutions that will work.

This stakeholder engagement analysis paper, therefore, is being provided to the Disability Royal Commission as a supplementary resource to our December submission. It outlines the methods we used for stakeholder engagement and sets out the key findings from this work.

In addition to the specific stakeholder engagement work conducted to develop the *Equal Pay, Equal Rights* paper, Inclusion Australia has been discussing issues about employment with member organisations and the Our Voice committee for many years, particularly over the last two years. We have provided input to the Disability Royal Commission through hearings, submissions, and responses to issues papers.[1] We have also provided input to the Australian Government on different parts of the employment system.[2]

Inclusion Australia thanks all the people with an intellectual disability, other people with disability, families, supporters and others for their time and expertise, and commitment to an inclusive employment future. The names of those interviewed and surveyed have been changed for this report, and their words are used with permission.

The *Equal Pay, Equal Rights* paper will be updated to include this stakeholder analysis and will be publicly launched as a research report by Inclusion Australia in 2023. Several additional papers will be launched at the same time, including an Easy Read summary.

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[1] https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-on-employment-of-people-with-intellectual-disability/; https://www.inclusionaustralia.org.au/submission/drc-witness-statement-on-employment-catherine-mcalpine/; https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-the-omnibus/.

[2] https://www.inclusionaustralia.org.au/submission/response-to-the-national-disability-employment-strategy-2/; https://www.inclusionaustralia.org.au/submission/disability-employment-system-reform-submission/; https://www.inclusionaustralia.org.au/submission/what-works/.

Key themes

A number of recurring themes emerged from the stakeholder engagement. These reflect what people with an intellectual disability, families, advocates, researchers and other experts have understood for many years about inclusive employment, and what works—and what doesn't—for people with an intellectual disability.

Again and again, our stakeholders tell us that:

- Wages are too low: people with an intellectual disability need to be paid a proper wage.
- There are not enough jobs for people with an intellectual disability in open employment.
- People need ongoing, individualised support to find and sustain employment.
- Employer attitudes and low expectations can be a barrier.
- The system is too complex: individuals and families who use Disability Employment Services, NDIS, Centrelink and other governmental agencies are overburdened with the significant administrative workload and inaccessibility of these systems.
- People with an intellectual disability want—and have a right—to feel safe at work, and to be included and belong in a meaningful way.

The data and analysis below contain many testimonies and stories about how these themes impact peoples' lives. While each person's experience is unique, these recurring themes are almost universal among them.

It is very clear, then, what needs to change in order for Australia to meet its obligations under Article 27 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD), and for people with an intellectual disability to be fully, fairly and equitably included in the Australian workforce.

We outline our detailed recommendations in this respect in our *Equal Pay, Equal Rights* submission to the Disability Royal Commission.

Elements of our stakeholder engagement

A multi-pronged approach to stakeholder engagement was used in this project. The approach was co-designed by the project team which included two project officers with an intellectual disability and experience working in ADEs and open/mainstream roles.

The stakeholder engagement method included the following activities:

- Project Advisory Group
- Interviews with people with have worked in ADEs
- Interviews with families
- Survey for people with an intellectual disability
- Survey for family members.

These are outlined below. The collected findings are provided later in this paper.

Project Advisory Group

The research report, recommendations and findings were guided by a diverse project advisory group (PAG) made up of people with an intellectual disability with experience working in an ADE, representatives from People with Disability Australia, National Disability Services, and the Australian Council of Trade Unions.

The PAG was chaired by Sonia Hume, a person with an intellectual disability, and the agenda was set by Sonia and Larry Simpson, the two project officers who worked on the research report.

The agenda and material for the PAG meetings was developed by Sonia and Larry and prepared in Easy Read format for all PAG participants.

The PAG met twice to discuss two big policy issues. The first was the issue of low wages, and what a possible policy response to higher wages should be. The group agreed on an interim transitional supplement to bring workers with disability's incomes up to the minimum wage while broader reform was undertaken.

The second meeting focused on where people with an intellectual disability could find employment outside of ADEs. A wide-ranging discussion was had, with significant expertise shared about where people with an intellectual disability had found work.

All levels of government were seen as an appropriate target, as were the disability services and employment sector.

The hospitality, catering and travel industry was the one private sector area that the PAG saw as already employing people with an intellectual disability and having a significant workers shortage. This has been included in the research report.

Policy recommendations on these two issues were tested with the PAG, and discussed, to ensure they are based in lived expertise.

Interviews

A range of structured interviews were conducted with people with an intellectual disability and their families between October and December 2022.

The interviews with people with an intellectual disability were done by the project officers, Sonia Hume and Larry Simpson, and by staff at South Australian Council for Intellectual Disability. The interviews with family members were done by Jackie Softly, who is a family member of a person with an intellectual disability. All three of our stakeholder engagement workers have extensive expertise and experience in a wide range of employment issues for people with an intellectual disability, including lived experience.

Ten interviews were done with people with an intellectual disability and 15 with family members. The questions for the interviews were developed by the interviewers and covered a wide range of issues. People were asked to talk about the barriers to employment they faced, and the specific measures that were good about employment and support. Families in particular were asked about navigating complex systems, which was a recurring theme.

People with an intellectual disability talked about a wide range of employment experiences, including working at Australian Disability Enterprises (ADEs). They were asked about what they liked and disliked about work in different settings, and how they felt about their work. The project officers also asked about the kinds of support at work that people with an intellectual disability wanted and/or received.

A range of family members of people with an intellectual disability were interviewed about the experiences they had had supporting their family member with an intellectual disability at work. These experiences included working in ADE, work experience, volunteering, working in open employment, and running a business.

Family members talked often about the barriers they experienced with a variety of systems intended to assist in finding work. They also talked about how the cumulative complexity created a significant administrative workload for them.

The information from the interviews directly influenced the development of the barriers and solutions sections, along with the key recommendations and executive summary sections of this submission. The themes from the interviews also strongly correlate to the academic research commissioned for this research, and previous research into the barriers people with an intellectual disability face at work.

The quotes identified with initials below are from the interviews, with names redacted for privacy reasons. Quotes are used with permission. Deidentified quotes are from survey responses.

Surveys

Inclusion Australia released two online surveys for a two-week period from late November to mid-December 2022 and subsequently from late January to early February 2023. One survey was designed to be completed by people with an intellectual disability, developed using Easy Read software Rix, and one survey was designed to be completed by families.

The survey links were posted widely across organisations of people with an intellectual disability and families via a promotional page on Inclusion Australia's website. Respondents were asked a range of questions about their experiences and their views on barriers and useful changes to systems such as the NDIS and the Disability Support Pension. The survey questions are included in Appendices A and B to this paper.

The questions in each survey did not replicate each other. Rather, the questions were tailored to each demographic and asked for personalised experiences of what it is like for people with an

intellectual disability to find and sustain employment from each unique perspective of individuals and family members respectively.

The surveys aimed to capture a range of data about what it is like for people with an intellectual disability and their families, including:

- Finding information about training, jobs, employment support and other options for work.
- Using Disability Employment Services (DES).
- Getting the Disability Support Pension (DSP).
- What kind of supports people have at work.
- Whether people had paid work.
- How much people are paid at their jobs, and how this impacts on their life.
- How people get to and from their jobs.
- How many hours people work at their jobs.
- What people like and don't like about their jobs.
- What people would like to change about their jobs and the supports they get.
- What makes it hard for people to find or keep a job.

Our findings

Experiences at work

In the survey, people with an intellectual disability were asked several questions about their experiences at their job, from how they travelled to and from their workplace, to what they liked and didn't like about it, to what they would like to change about their job. 88% of people with an intellectual disability who responded to the survey had a paid job, with 6% saying they used to have a paid job. 5% had never had a paid job.

Of the people who had paid work, 79% of people worked at an Australian Disability Enterprise, while 15% worked in open employment. 6% didn't know whether or not they worked in an ADE.

Similarly, in the survey for family members, the majority of respondents said that their family member gets a supported wage in an ADE (43%) or a standard wage (at least minimum wage) in an ADE (3%).

19% of respondents' said their family members got a standard wage (above minimum wage) in another kind of job in open employment, and 8% got a supported wage in another kind of job in open employment. 19% of respondents said their family member did not get paid and 8% said their family member relied on the DSP only.

Of the 171 people with an intellectual disability who provided details about the kinds of hours they work, 40% of respondents worked between 20 and 30 hours per week. 21% of respondents worked more than 30 hours per week, with just 8% working fewer than 10 hours per week.
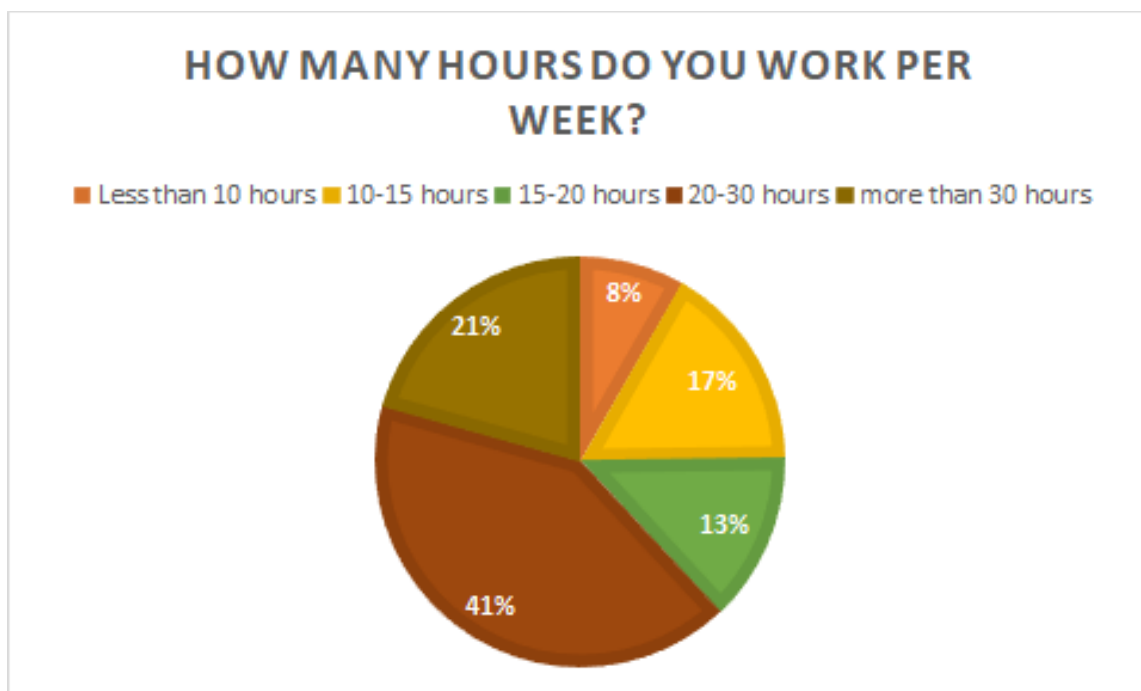
Working in an ADE

The vast majority of people who worked at ADEs said that they liked their job. When asked what they like about their job, almost all respondents said it was the friends they made. People said:

- "Being with my friends and workmates and being supported by the staff, being in a safe supported environment".

- "I am not bullied and I feel safe."
- "Friends, safe, fun, variety, self-worth, active."
- "I'm valued, I'm treated like everyone else…I learn new things. They believe in me."
- "My friends are there. I like to talk to lots of people. I can do this work. The supervisors are always around. If I get too stiff or tired I can get up and walk around…"
- "I cannot drive so getting picked up and dropped home is great. I like that I have a regular job with people who know and understand my particular needs. I am looked after by my work supervisor."
- "The friends I have made and the sense of belonging."
- "I feel safe, secure, my friends are there, the staff help and support me all the time. I fit in, nobody bullies, I feel accepted and love working with people who are like me. I can do all the work given to me and know if I need help it's there right away."
- "Working with all my friends."

For many respondents, their job was the source of their social connection, and it made them feel safe. People who worked in ADEs overwhelmingly said they felt safe and had their support needs met. The friends they made gave them a sense of belonging and that they fit in.

This underscores the importance of ensuring that people have access to ongoing, individualised supports that meet their needs, as well as an inclusive environment in which people feel they belong and are socially connected.

This further substantiates the results in the family members' survey that said the major factor that makes it hard for families to support their family member to find or keep a job are employer attitudes to people with an intellectual disability.

We know that discrimination, harassment and negative attitudes are daily experiences for people with an intellectual disability across many social contexts, including work. This is illustrated by this survey respondents' remarks: "I've tried open employment roles so many times and I face discrimination, exclusion and bullying."

Internationally, there is significant evidence that one of the key predictors for finding and keeping a job in open employment is the presumption of employability among parents, educators, the workforce, employment services and the wider community.

The survey results tell us that people feel that ADEs provide a safe, supported environment for people with an intellectual disability, and this needs to be replicated in an open employment context so that people also have greater access to job opportunities in the open workforce.

When asked what they did not like about their job in the ADE, two key themes emerged:

- They were not being paid enough.
- Getting to and from work was difficult.

Many people with an intellectual disability rely on public transport to get to and from work. Indeed, around half of people with an intellectual disability who responded to the survey relied on public transport for work.

There are ways to make public transport more accessible for people with an intellectual disability, which are detailed in the *Equal Pay, Equal Rights* report.

Other reflections on what people didn't like about their job in the ADE included:

- "Not enough pay, having to do more jobs than others because I'm a highly skilled worker while my co-workers are not able to do it—can be very physically demanding."
- "More money would be nice."
- "The pay could be looked at and the conditions of where I work could be updated—it's old."
- "Sometimes it is too repetitive."

People who were interviewed by our project officers also talked about some of their positive and negative experiences at ADEs. C said that they liked the work they did in ADEs because they got help from "Supervisors and all the different jobs we do there" and "I like my friends and my boyfriend at my job." They said they didn't like "if there's any fights, or people blaming me for stuff" and "I don't like being bullied and not being listened to."

H said being "paid $3.73 per hour and sometimes isn't enough. My mum pays my bills." Others said they "felt a bit down and I wanted to get out [of the ADE]. I wanted to stay in bed." G talked about the low wages they received, saying "once my boss heard about supported wages they said no you can't do the job as well, so I have to agree with it or lose my job. [I was told] You're better off to agree with it and to have a job. So I agree with it, but it really made me put me down in the gutter."

J summed up both the positive and negative aspects of working in an ADE, saying "I felt happy because I got to meet new people [when working in the ADE], to get along, because, if I didn't get to meet people then I would be stuck at home with nothing else to do. [Working in the ADE] was not very good, because I would get like a dollar an hour just the work and then it's all work. You didn't get enough money, then you can't earn a lot of money."

For many families, working in an ADE was something their family member with an intellectual disability had done, and people had a variety of experiences with ADEs.

Family member M said that "He seems to really love it. So it's obviously a combination of the familiarity, the routine. And because he's not very social because he doesn't have very good language, he gets to wear all the safety gear. So he's got his headphones on, so it's not really the opportunity to talk, which I think really suits him." M also found that "they could be doing a whole lot more in the life skills area and stuff like that, the customised employment or all those pre-work skills. They've got all these people, sitting right there in their hands. They should be saying, "Hey, look at us. Yeah, you know, look what we can do with these people." Instead of just keeping them, you know putting knife and forks in plastic bags."

Family member C said that "she went straight to [ADE] from school. And she was full time. Which actually, you know, in, in my experience, that's fairly unusual to be doing five days a week. But, you know, she clearly wanted to be out there doing that. And it worked for us as well. And she went from strength to strength and, you know, started off at the lowest level and worked her way up to what she was doing the headsets, yes. And then worked her way up to the cutlery."

For some families, ADEs didn't work or were bad places to work. Family member M said that "K was actually rejected from the ADEs that we applied for because he was insufficiently independent to work at those. And so on that basis, we pursued open market employment instead."

Family member L said "he was [at the ADE] for a long time, awful place, got treated like crap. You know, not respected or trained or supported. He was sexually abused by somebody and they did they just didn't know how to handle it"

Family member A said that "if the work is important, then pay proper wages, pay living wages, don't pay lip service, because it then tars every single person with a disability, not just the people that go to those ADEs."

Experiences in open employment

When asked what they like about their job, survey respondents who had a paid job in open employment reported **the same things as people who worked in ADEs**. That is, the friends they made.

In addition, there were some themes mentioned by those in open employment that were not mentioned by people who work in ADEs, such as:

- Being paid a proper wage.
- Purpose and meaning.

Some reflections from survey respondents about what they like in their job include:

- "I like my job and my friends and the routine of working."
- "The people and my purpose."
- "The staff are so nice and friendly and the work I do is really helpful and meaningful and it's not just work that is basic like cleaning tables I'm actually a big part of the team."
- "The money."
- "Variety of different posters/videos to make. Engaging with my support worker wile I am working during my shift."
- "We do different products and I have flexible work times and I work with interesting people."
- "I like working hard, making friends and the boss is really nice."
- "Like any workplace there's a clash of personalities and we don't always get along but I deal with it the best way I can and I do have lots of support."
- "Being paid the award rate makes me feel appreciated and that I can do the job."

We can surmise from this qualitative data that **the positive outcomes of work are the same at ADEs and in open employment**: namely, social connection, friendship and belonging.

The biggest difference in terms of positive outcomes is that in open employment, people are paid a living wage and, based on the reflections from people with an intellectual disability above, people tend to have greater flexibility and variety in the kinds of work they do.

These factors—which based on this data appear to be absent from experiences in ADEs—generate a greater sense of meaning and purpose.

When asked what they didn't like about their job in open employment, the majority of people answered "nothing", while one response mentioned being bullied. Once again, this is evidence that there is much work to be done in building capacity within the workforce to change negative attitudes, provide training for employing people with an intellectual disability, and creating inclusive environments.

Other employment models

Microbusiness were an employment option many people with an intellectual disability had explored.

J talked about the barriers they face in getting a job outside of ADEs, which led to starting their own business instead. They said "Because it is very, very hard for me to get jobs, like to do work and with

a disability, find a job, it's not that, it's not easy. So, that's why I got help so I can get a proper job and get, you know, get paid and stuff to do my own jewellery business."

K had done the same, saying "I have a cookie business, where I sell the cookies, collect money, stamp the boxes, talk to people and pet their dogs."

Family member J said "The full launch of her business may not be until February, March next year. Because we have to get it right for M. But then there's a bigger audience at stake. We have to get it right for her because she could be the influence that shows other people with significant disability, they can take their place genuinely in mainstream business and community life."

But there is often a big workload for families. Family member T said "if [a microbusiness] is what you want to do, I think you should be able to go into it, like really clearly, but also understanding that that might require, like the whole family effort, not just the one person effort, and then it needs to be funded that way."

Income and cost of living

Our survey for people with an intellectual disability asked how much respondents earned per hour at their job. Only 31% of our 200 respondents answered this question. Of those who answered, 74% were paid less than $10 per hour, with 16% earning more than $20 per hour (see chart below).

HOW MUCH DO YOU EARN PER HOUR?
- 3% $40-$49
- 5% $30-$39
- 8% $20-$29
- 10% $10-$19
- 74% Less than $10
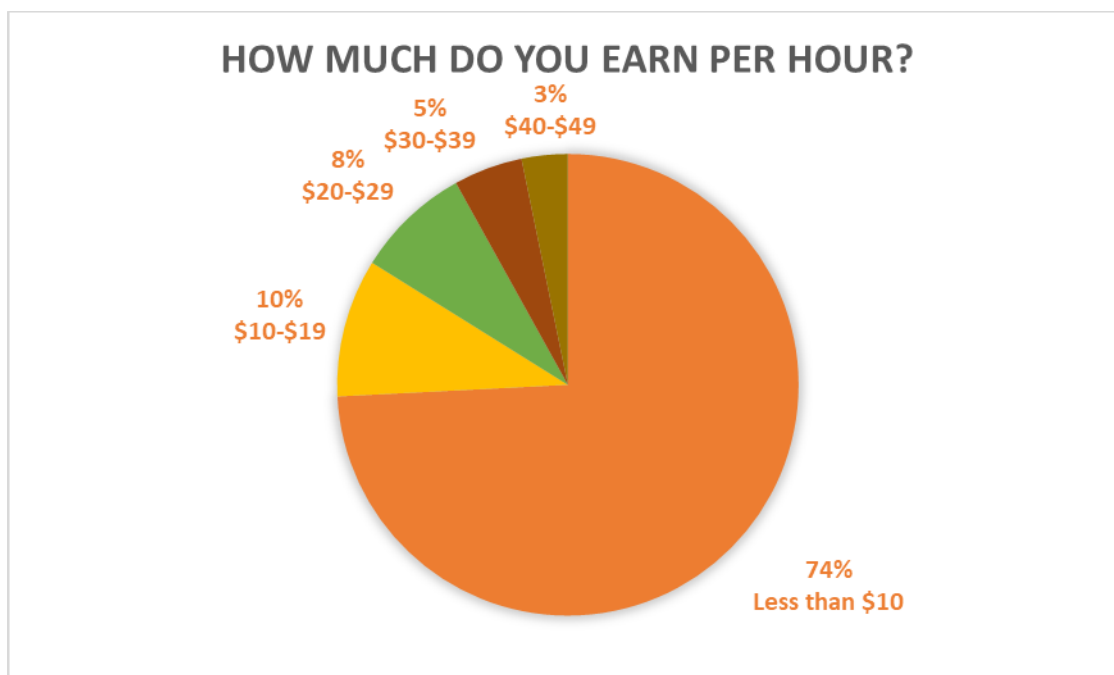
All of the respondents who earned less than $10 per hour (n=46) worked at ADEs.

In the family member survey, respondents were asked whether their family member has enough money to live on, combined from the DSP and any wages from a job. The results covered a range of personal life experiences, such as whether they live at home with family, are about to move out, or live independently. Slightly fewer than half of respondents (48%) consider their family member has enough money to live on:

- 31% of respondents said their family member had enough to live on and they lived with family at home
- 17% said their family member had enough to live on and lived away from family

- 23% said their family member did not have enough to live on and they lived with family at home
- 13% said their family member did not have enough to live on and lived away from family.

Families included comments in the survey about the impact that not having enough money has on them and their family member with an intellectual disability:

- "Trying to live in Sydney away from family, always running out of money, working more hours only to then get pension (DSP) cut, wanting to socialise but not having enough money, needing to ask for money from family which is embarrassing but also then placing pressure on another household."
- "Financial stress and inability to be independent."
- "High stress, loans, debt, more illness."
- "Sitting just above the poverty line right about now."
- "We support her fully. She doesn't get the self-esteem that goes along with having her own money."
- "We supplement which affects our retirement options."
- "We are required to fund many and various needs within his life. Our utility bills are astronomical as he is home often since the pandemic commenced."
- "Both parents have to work past retirement to support the member."
- "They cannot move out of home."
- "Huge stress particularly on unpaid carers."
- "Financial impact as we subsidise her income so she can continue to save more for housing purchase."
- "They would have to stay home and do nothing. We can't afford to support him. We have our own retirement and life as well as helping out two other sons."

When people with an intellectual disability are systemically kept from earning a proper wage, the impacts are financial, social, and emotional. It takes away peoples' choice and control, their ability to live independently and take part in social and community life just as people without disability would.

As these reflections demonstrate, when people with an intellectual disability are denied a living wage, the economic and emotional flow-on effect often falls on families. The stress and emotional labour of financially supporting family members who cannot earn enough to cover their own expenses is writ large in these testimonies. This underscores the point that paid work is about more than earning a decent wage: it is also about the respect, self-esteem and sense of self-worth that comes with being paid fairly.

Barriers to open employment

Survey respondents and interviewees identified a wide range of barriers to finding and maintaining open employment. These are discussed at length in our *Equal Pay, Equal Rights* submission. Key themes and stakeholder quotes are included below.

Responses to our family survey indicate family members think that the two major factors that make it hard for **respondents' family members** to find or keep a job are:

- Employer attitudes to people with an intellectual disability (47%)
- Not finding a job with the right support (47%)

They reported there are other issues that also create barriers for people to find and keep jobs, including:

- Lack of information about jobs and support (37%)
- Lack of available transport (32%)
- Reporting to Centrelink fortnightly (26%)
- Not finding a job they like (23%)
- Concern about losing the Disability Support Pension (21%)
- Difficulty getting NDIS supports (18%)
- Difficulty getting DES (11%)

The responses tell us that the system is inaccessible and far too complex. Agencies such as DES, Centrelink and the NDIS are siloed, and their systems do not interface with one another. There is also a clear lack of individualised support and job customisation for people with an intellectual disability.

When asked what made it hard for **family members themselves** to support their family member to find or keep a job, the answers were much the same. The number one issue that made the process hard was:

- Employer attitudes to people with an intellectual disability (56%)

Followed by:

- The time it takes to support family member (46%), and
- Navigating different government systems (39%).

Lack of choice

Families spoke strongly about the polished pathway, about how they felt they had few choices when supporting their person with an intellectual disability to make the transition from school to work.

Family member K said "when people hear that he is in open employment and has been there for four plus years, they think well, that was it a smooth run from school, you know, some magic bean, but there was a lot of pain and I can remember coming out of one meeting driving him home after a specialist disability ADE meeting, crying and apologising to him that I've ever put him in that position."

Family member M found that work experience was at the local ADE and said "the conversation was that they were quite happy to put him on once he'd finished school. So I thought, "Oh, well, I'll keep that in mind because that means that I'll have something for him to do" because we were transitioning on to NDIS at that point, so, yeah. And there was no services. There was really nothing happening down here. So I thought at least I can give him two days a week of routine, because to me, that was what was more important, keeping him in that routine of getting out of the house."

Family member J said that change "needs to start with the school because all they do, they have all these employment sort of meetings and they used to put on a big morning tea and everything. But the only people they bring in are ADEs."

One survey respondent with an intellectual disability noted, there are "not enough employers offering opportunities for people with intellectual disability." Another said, "I am never given a job unless I have someone helping me and I want to get it on my own merits."

System complexity

Families talked a great deal about how complex all the various system were to engage with, and to get support.

Family member M said "It seems to be up to us to go and source everything else [for employment support], like we've had to with speeches, teachers and OTs and all that kind of stuff."

Family member K said that "I must have gone through half a dozen organisations before I chanced on one. And I can remember I sat at our dining table, and I was crying, and he was crying."

For family member L, the administrative load is like "another job. I have to invest many hours a week in order for her to have her current lifestyle that she has. I have to get into the NDIS platform every week and pay all the invoices, I have to book all the HireUps, I have to make sure I'm engaging with the employer when there's anything going on that they want her to know about, I have to report to Centrelink every single fortnight. Every single day I am doing something C. Something C. I say to my husband all the time, If I dropped off the earth tomorrow, what would happen to C?'"

Lack of ongoing support

K talked about how difficult it is to get the support they need to get and keep a job saying that "I find [disability employment services] will have it you on the books as a number than actually look for work. Is in my experience in this is basically, it comes down to is like I could work, go to work, or we need your wage your pay thing. So we can send off to the government because they get paid. That doesn't mean they're actually finding me a job."

G was clear about what needed to change saying that employers needed to "Listen to them, help people with a disability to aim higher then give them the right support".

B knows what the right support is at work, saying "I got my job online, and applied with help from my Mum and my caseworker. I like that there is friendly staff and very enthusiastic people. Great to work from home sometimes when there's opportunities. And things are in Easy read."

Many families talked about how hard it was for their person with an intellectual disability to find a job outside of an ADE.

Family member J said "We have got significant [NDIS] support. She could have a job and we would have the support to support that job. The problem we've got all this support, we can't find anything to do with it, because she hasn't got a job."

Family member E said "His first year after high school, he made it pretty clear, he did not want to go [to the ADE] as part of his week. And so it was like, well, what are we going to do with you? And I didn't know about TAFE options at the time. So he stayed home a lot of the time, and we went out together a lot. It was hard going because I felt I've got to keep you active and fulfilled."

Family member L said "supporting someone in a cozy little, little ADE is a lot, probably a lot easier than actually getting knocked back and trying different things and trying to break down barriers and all those sorts of things."

Getting information

Most people with an intellectual disability who responded to our survey reported getting information about work from friends and family members (54%), followed by their school (14%). Just 5% of respondents said they got help from DES. People also said they got help from advocacy organisations, support workers, or mental health services.

From family members' perspective, before their family member started work, they got their information about jobs, employment support and other options primarily from other families (38%), followed by their family members' school (35%). This was followed by disability service provider (30%) and Disability Employment Services (DES) (30%).

When asked whether this information was helpful in working out employment options, responses were split 50/50.

When asked how easy or hard it was to find information about employment, 86% said it was hard. Family members who were interviewed also reported information is hard to find. MM said: "I understand completely why so many people fall through the cracks and don't get all the services that they're entitled to, because nobody gives them information. It's not readily available anywhere. And I think that's a real blight on our services, Services Australia or whatever the hell they're called. It's not good enough."

Lack of workplace training options

Many people with an intellectual disability found it difficult to access work experience or after-school paid work, and many also had a negative experience.

Family member K said "He did work experience in this landscaping place. Got there in the morning. They said to him, can you go out there and work at this table and rearrange it and everything. I picked him up a couple of hours later, he was sunburned. He hadn't been to the toilet, he didn't have a drink because nobody came back to him and said, if you need a drink, go and take a break. He didn't want to go back and I don't blame him. We had a succession of those kinds of work experiences."

Family member T said it was hard to get an after-school job - "she wanted a job like the other kids had, because they all had their part time jobs. So I traced around with her to the local McDonald's, Pizza Hut taking her resume but you know, she never got responses back."

Family member L said "she did some work experience in catering. And that was a terrible experience. They were very proactive about wanting to support people with disabilities in the workplace. And I was super excited about it. I went down with the school, everything looked hunky-dory. I did up a good storyboard for C in the workspace. So, 'These are all the tasks that you'll be doing, and you'll tick them off as you go along,' and we practised all of the tasks at home, like polishing cutlery, and things like that. So she understood what she was going to be doing in the environment, and she was doing that for about four months. But at the end, she had taken a million photos of herself in that workspace over those four months, and there was not one single photo of someone else in it. So she had been standing in the backwash area, by herself, for four months, polishing cutlery, and no one engaged with her."

Some people with an intellectual disability were offered work experience in an ADE. A said "they went as a group [to the ADE] in their first lot of [work] experience." Family member E said "Really, it seems to have boiled down to going to [an ADE]. An aide from the school would be assigned to take him and stay with him during the afternoon while he was doing whatever he was trying out packing headphones."

Other people with an intellectual disability didn't get any work experience. T said "She didn't get any work experience at school because they didn't think there would be anything she could do. Their whole focus was more on recreational. When L left school, it was just kind of assumed that she would just go to like a day service type thing."

Getting to and from work

Transport was often mentioned as a significant barrier to employment. Family member T said that "She was a very competent bus traveller. until about three or four years ago, the transport system here decided to change the timing and the routes of all the bus things and they've made these strangest routes. So consequently, K lost that skill, she doesn't like the new way and doesn't suit her timetables."

Others found it hard to get funding for transport from the NDIS. Family member M said "We just spent 18 months, 20 months at AAT. I had to fight. So we've got transport funding for him to go to ADE, so we've got 11,000 odd in the transport budget. Because I said, "Well you're funding him to go to ADE. You need funding to get there," I said, "because I'm not taking him, it's not my job.""

Family member L said "I use her NDIS funding for a taxi service to get her to work. So travel, for me, transport, access to and from work is a big deal for people who may not need a lot of support in the workplace, but need to get to the work. They need to get there."

Other employment models

Microbusiness were an employment options many people with an intellectual disability had explored. Family member J said "The full launch of her business may not be until February, March next year. Because we have to get it right for M. But then there's a bigger audience at stake. We have to get it right for her because she could be the influence that shows other people with significant disability, they can take their place genuinely in mainstream business and community life."

But there is often a big load on families. Family member T said "if [a microbusiness] is what you want to do, I think you should be able to go into it, like really clearly, but also understanding that that might require, like the whole family effort, not just the one person effort, and then it needs to be funded that way."

J also talked about the barriers they face in getting a job outside of ADEs, which led to starting their own business instead. One person said "Because it is very, very hard for me to get jobs, like to do work and with a disability, find a job, it's not that, it's not easy. So, that's why I got help so I can get a proper job and get, you know, get paid and stuff to do my own jewellery business."

K had done the same, saying "I have a cookie business, where I sell the cookies, collect money, stamp the boxes, talk to people and pet their dogs."

Income support and other services

Disability Employment Services (DES)

Stakeholders identified significant challenges with the DES system.

Disability Employment Services didn't work for K and his family member A, who found that "because the policy with the DES was that after 12 weeks support was basically withdrawn because of the policies that they ran. Funding to them was curtailed. And so then, you know, so K was at Sizzler, for a good three or four years, yeah, really the works. When he's at work, he works. And he's very loyal. But anyway, so because he'd been there so long, they withdrew the full support. And he was only given support again when he decided that he wanted to move on."

Respondents to the family members' survey also identify challenges. Almost a third of respondents said they found information about jobs, employment, and other options from DES providers before their family member started work – but of these, 72% did not find it helpful. Some comments listed by respondents in relation to DES include:

- "DES was all but useless – only gained employment at ADE from info from other families."
- "Absolutely not – we had to beg, steal and borrow to get anywhere – 9 years of heartache."

Of those who used DES as a resource to help their family member find employment, most people used them for finding a job (60%) and getting ongoing support at work (32%). Less than 5% used DES for thinking about a career, which demonstrates the lack of individualised support for job customisation and professional development.

National Disability Insurance Scheme (NDIS)

The NDIS was particularly problematic in regard to employment support, with many families saying that employment supports weren't reliable or flexible or responsive to what was needed.

Family member K talked with an NDIS planner and said " I don't need SLES funding, what I need is to be able to use the hourly rate for finding and keeping a job. Because I thought that's what that was there for, and she said, No, that's not what that's for. So But what's a for, she said, Will you need a SLES program. He's done to three SLES programs, he doesn't need another SLES program, he needs an in funding for individual supports, and we can actually pursue what he wants. It's always been about these programs that are pre-existing, as opposed to what does he actually need"

Family member L said "They cut it a little bit [from her NDIS plan]. They took a little bit out. I had to fight though to keep it because I hadn't used a lot of it during COVID. And when I met with my support planner or whatever they are, the planner, she said, Oh, you haven't used much. It's gonna be hard to keep it." And I said, "Whoa, whoa, whoa, whoa. We've had COVID, she hasn't been able to work because her workplace was shut down, shut down for 20 weeks, 22 weeks. So she had no employment, so I couldn't utilise that money. "

Family member J said "some person in the [NDIS] plan management agency has said we need reports from therapists. I'm going, what are you talking about? It's not a therapy goal, it's an employment goal. You're not even making sense. So, I'll fight it all the way to the tribunal if I have to, because that's just the way I'm made."

Family member M said that "in the last couple of years, the very suddenly our interaction with NDIS have become extremely adversarial. And it's really like all of a sudden there's this agent, I'm talking to people who in my opinion is that they clearly regard their jobs as having to defend the agency against people like K, right? And so prior to that, I was kind of thinking, you know, the future for K is you know, there's an agency here and a support network that's gonna work pretty hard to make sure that K's OK. Now, I'm like, ugh, actually maybe not. And so now that worry about what exactly is gonna happen to Ken after we die is you know, back on the front burner, really."

M also found that employment supports were removed, and fears that "there's a non-official move there to try and steer people with cognitive, intellectual disabilities to institutional care. They don't want to support community supports for people like K."

Family member A had the same experience, saying that "So [the NDIS] took away everything. Yeah. So like, all his capacity building was gone. All these finding and keeping job [support] was gone. His support coordination was gone, transport funding was gone. Everything. So basically, we've got a

choice. We fight that. Or we wrap the business up, because or and as you've already said, you we walk away from our jobs, and become his informal supports."

Disability Support Pension (DSP)

The challenges of dealing with Centrelink around the Disability Support Pension was another common theme from our stakeholder engagement.

87% of people with an intellectual disability who responded to the survey said they received the DSP, while 8% did not, and 5% were not sure whether they did.
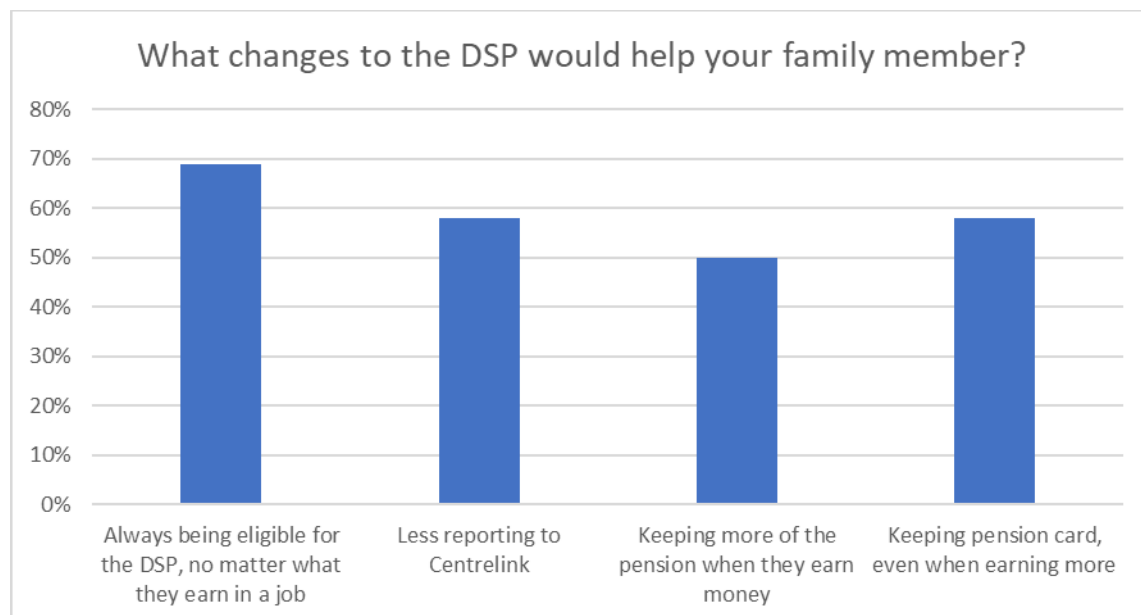
Of the people who responded to the question, "is the money you get from the DSP enough?" (n=7), 85% of people said it was not enough. When asked what they would do if they had more money, people said:

- "Eat and pay bills properly, get exercise."
- "More money would help me pay my bills and live a good life."
- "I would be able to go places and go to basketball matches. Have a better social life."
- "Do more activities, bet healthier, save. Same as those without a disability who get paid."

In the survey for family members, 64% of respondents said their family member received the full DSP, while 26% received a part pension. Concern about losing the DSP was raised as a barrier to supporting family members to get a job. Family members listed a number of changes to the DSP that would help them and their family member (see graph below).

Chief among these is a change to the eligibility criteria: people should always be eligible for the DSP no matter how much they earn in paid work.

That 58% of respondents wanted less reporting to Centrelink also points to the complexity of systems and the excessive amount of time it takes to navigate these systems.

What changes to the DSP would help your family member?

Change	Percentage
Always being eligible for the DSP, no matter what they earn in a job	69%
Less reporting to Centrelink	58%
Keeping more of the pension when they earn money	50%
Keeping pension card, even when earning more	58%

These findings were supported by comments from family members who were interviewed.

Family member K said "I don't know how anybody who truly has an intellectual disability manages reporting. My husband is a fairly intellectual kind of guy, and he would lose the plot. Like it's just ridiculous anyway, so I manage that for him."

Family member L agreed, saying "The whole Centrelink reporting just absolutely blows my mind. I go into that portal every fortnight to do her reporting and I think, how could she even log into this?' The questions that they ask her, like, How many hours did you work between this and this?" is easy, but when it comes to the money, it is hard, because her pay period is different to the reporting period. And I think, "My God, if I don't do this, how could she possibly?" And they want the person with the disability to report what they're earning. That system is so far flawed, it's ridiculous. I've had days where I've had a panic on because it's six o'clock at night and I've gone, Oh my God, I forgot to report. Oh, oh my God. If I don't report, she's not going to get a pension. Oh my goodness. It's terrible."

The interaction between the Disability Support Pension and wages was discussed. Family member M said "Of course, I would like to see him earn a real wage for his work because $3.29, it's gone up quite a lot the last year, you know, a few cents each fortnight. But again, I am concerned about the impact on the Disability Support Pension because well, you know what it's like in terms of earn too much, you've got to report it and all that kind of stuff, you know. He can't do that. That's an added burden on me if I've got manage all that again."

Family member M said "if we miss like a reporting deadline for his you know for his 10 or so hours a week then yeah, then he has interruption in his pension. We actually had it cancelled once and we had to go through the whole process, because we missed it by like a week. Cause we just forgot, especially early on you know, we were trying to figure it out."

Hopes for the future of work

Through the surveys and the interviews, people with an intellectual disability and their families were asked what changes they would like to see, and what hopes they have for the future of employment for people with an intellectual disability.

We outline responses from families first below, then finish this paper with reflections from people with an intellectual disability themselves.

From families

In the families survey, respondents were asked what kind of help or support would make the most difference to them to help with their family members' employment. Overall, the following themes emerged:

- "Pay award wages."
- "More ongoing, individualised support."
- "Change in negative community attitudes."
- "More options available for open employment with the right supports."

Other reflections from family members included:

- "Better funding for ADEs."
- "An education system designed to see the potential of people with intellectual disability so that it genuinely endeavours to prepare them for meaningful and suitable work (and by suitable I mean something that meets the talents and interests of the person)."
- "Less reporting to Centrelink—make it more streamlined with the Australian tax system, and let them earn more without fear of losing their pension and benefits."
- "Simplify the process, easy accessibility, less red tape and greater support."

- "More employers willing to take on employees with a disability. Employers need more support, help, training to achieve this."

Family members of people with an intellectual disability looking for or in paid work were asked what three changes to NDIS employment supports they would make. Again, the most commonly raised changes were:

- More ongoing, individualised supports.
- Employment supports need to be person centred.
- Make it easier to navigate.
- Make sure people get paid at least the minimum wage.
- Work with employers to grow their capacity and provide training.

Many respondents also said that ADEs need secure, ongoing funding and that more training and work experience options should be provided during school.

Family members expressed many hopes for the future for their family member in employment, many of which reflect the same hopes people with an intellectual disability have for themselves:

- "That something comes along that he would love to do and gets the support he needs to achieve greatness."
- "Meaningful and successful employment in a mainstream environment."
- "I hope she is able to work with people that become her work family and she is working in an area she is passionate about and loves."
- "To not be discriminated against in open employment based on their disability instead of their ability."
- "Getting more hours."
- "That she can continue to work in an ADE that accepts her as she is while encouraging her to progress in whatever small steps she can."
- "That she could find a job that she enjoys and finds fulfilling, with appropriate supports and job security and where she would feel included."
- "That they find work that is meaningful and fulfilling, and that they can derive pride and dignity from the work they do and the opportunity to play a role in society."
- "Continuation and progression. A growing feeling of self confidence and self worth."
- "Savings, superannuation and owning a unit one day, perhaps even a house with a family. One day himself even giving back and helping others by employing people with disability in his own business."
- "Enjoyable and meaningful work compensated fairly."
- "Permanent employment on a supported wage in open employment."
- "I don't want her to feel as though she has no future which is exactly how she is feeling. It is bleak. With no direction or support. She is so negative about her future and feels pretty hopeless."
- "Paid job 5 days a week—like everyone else!"
- "Full employment in mainstream community with award wage, no loss of government support (particularly health care card)…no red tape to deal with…a society where merit based employment actually treats them based on merit, no preconceived ideas about what they think they can't do."

From people with an intellectual disability

When asked about what else they would like to tell us about working at a paid job, people with an intellectual disability reflected on their hopes for the future of paid work and what changes they want to see.

Some people with an intellectual disability wanted more opportunities to do different kinds of jobs. In their interview, K said they worked "at Coles, breaking up boxes, tidying up, putting things in the bin." T said they "like coming into work each day and seeing the people. Every day is a new day a bit of a challenge, which I like about the job." Another person said "I would like the government to employ them. And have easy read or plain English. And show how you can grow to go to the next level so you can be a team leader. And once you're a team leader, if you wish to what's the next step to go up higher. So you're slowly being, growing and moving on."

Several survey respondents identified the gaps in opportunities and the inequity for people with an intellectual disability currently, saying:

- "Be fair, pay people with disabilities a fair go. Support people with disabilities to be part of all the community, not just the disability network."
- "Stop abuse, neglect, exploitation and fraud."
- "We need equal pay for gender gaps."
- "Hopefully in the future people with disabilities get paid better and better working conditions."

In their interview, H supported this feeling, saying "I want to feel included and be listened too. And get fair pay." Survey respondents also said "I like meeting new people and feeling like I've done something to achieve something. I don't want to be a burden," and "just that I love having a paid job [that is] very meaningful and productive."

One survey respondent summarised it by saying, "we got a lot of work to bridge the gap between people with disabilities and regular society" while another said their hope is that people with an intellectual disability can "feel like the rest of the community and have the same opportunities as others."

Appendix A. Survey questions for individuals with an intellectual disability

1. What state or territory do you live in?

2. How old are you?

3. Are you on the National Disability Insurance Scheme (NDIS)?

4. Do you get the Disability Support Pension (DSP)?

5. Do you work in a paid job?

6. What kind of work do you do at your job?

7. How long have you worked there?

8. Is you job at an Australian Disability Enterprise (ADE)?

9. How did you get your job?

10. Did you have help to find your job? If Yes, who helped you?

11. What do you like about your job?

12. Is there anything you don't like about your job?

13. Do you get support at work to do your job? If Yes, from who?

14. How many hours do you work each week?

15. Do you know how much you get paid per hour?

16. If Yes, how much do you get paid per hour?

17. What things do you have to pay for each week? For example paying rent or board, buying groceries, savings

18. Do you have enough money to pay for these things?

19. Are you happy with how much you get paid for your work?

20. How to you travel to and from work?

21. Have you had a job somewhere else before? If Yes, why did you leave that job?

22. Do you want to get a different job?

23. If Yes, what type of job would you like to do?

24. Is there anything else about working at a paid job that you want to tell us?

25. Would you like to get a paid job?

26. What did you do for work?

27. How long did you work there for?

28. Why did you stop working there?

29. What did you like about the job?

30. Was there anything you didn't like about the job?

31. How many hours per week did you work?

32. Did you have support at work to do your job? If Yes, who supported you?

33. Were you happy with how much you got paid at your old job?

34. If No, why not?

35. If you get the Disability Support Pension (DSP), is the money you get from the DSP enough?

36. If No, what would you do if you had more money?

37. Is there anything else about working at a paid job that you want to tell us?

38. What kind of job would you like to do?

39. Have you tried to get a job?

40. Have you had help to look for a job? If Yes, where from? For example NDIS, family member

41. What has made it hard to get a job?

42. If you get the Disability Support Pension (DSP), is the money you get from the DSP enough ?

43. If No, what would you do if you had more money?

44. Is there anything else about working at a paid job that you want to tell us?

45. Why don't you want to get a job?

46. If you are on the Disability Support Pension (DSP), is the money you get from the DSP enough?

47. If No, what would you do if you had more money?

Appendix B. Survey questions for families

1. Which state do you live in?

2. Which part of your state do you live in?

3. How old is your family member

4. Does your family member work in a job?

5. Is your family member an NDIS participant?

6. Before your family member started work, where did you and they get information about jobs, employment support and other options?

7. Was this information helpful in working out employment options?

8. Was it easy or hard to find information about employment?

9. Before your family member started work, what kind of preparation did they have?

10. If your family member is working, where do they get support from to do their job. Select all that apply

11. Has your family member used a Disability Employment Service (DES)? What did you use them for?

12. What has made it hard for your family member to find or keep a job?

13. What has made it hard for you to support your family member to find or keep a job?

14. What kind of income does your family member get?

15. Does your family member get the Disability Support Pension (DSP)?

16. What changes to the DSP would help your family member?

17. Does your family member have enough money to live on, from the DSP and any wages from a job?

18. If they don't have enough money, what impact does this have on them, on you and on your family?

19. If you could make three changes to NDIS employment supports, what would they be?

20. Describe the type of help or support that would make the most difference to you to help with your family member's employment?

21. What do you hope for the future of your family member with employment?

22. Is there anything else you would like to say about employment?

23. If you would like to be updated when the report is published, please include your email address below.
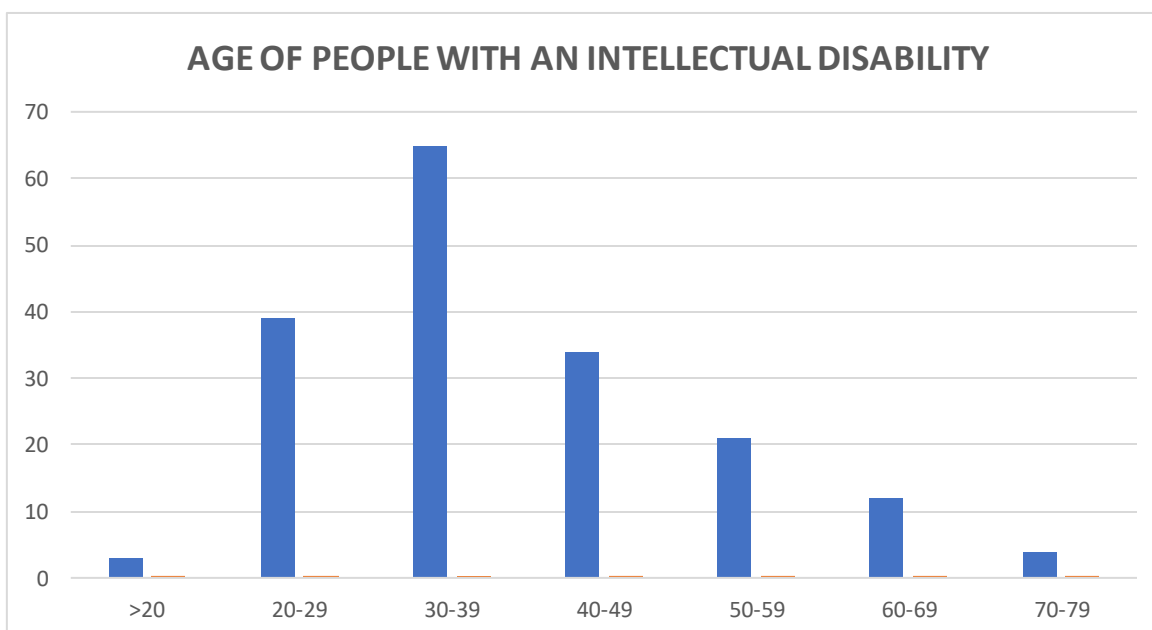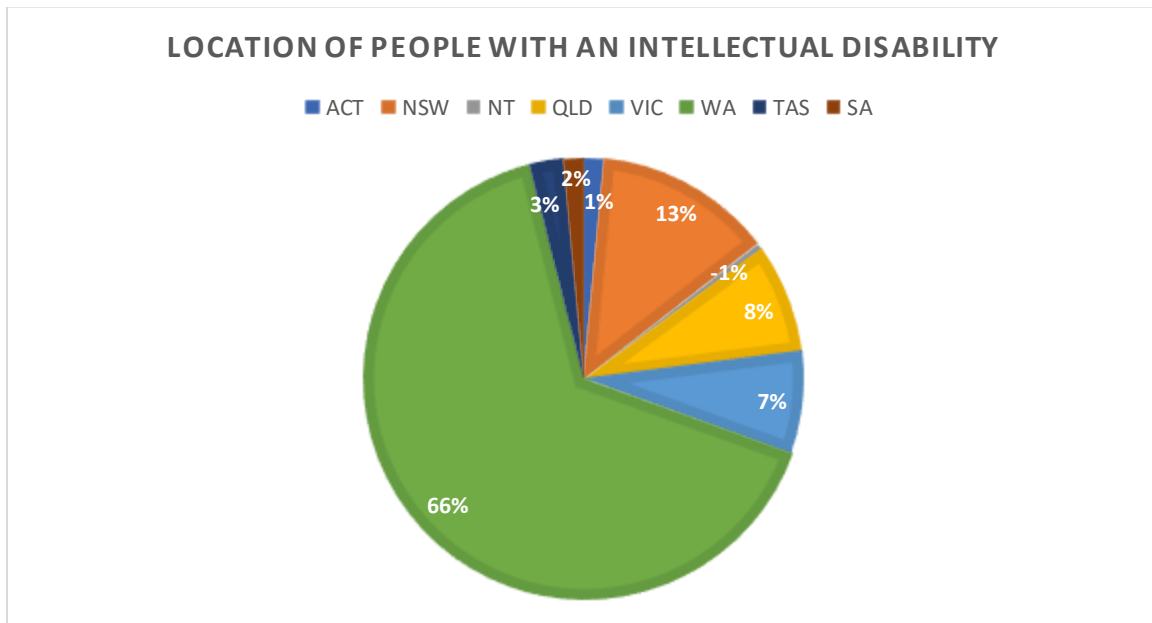
Appendix C. Survey response demographics

People with an intellectual disability

We received a total of 200 responses from people with an intellectual disability during the survey period.

More than half of respondents were from Western Australia, followed by 13% from Queensland. Respondents represented a broad age-range, between 16 years to 70 years, with most people aged between 30-39.

92% of respondents were NDIS participants.

LOCATION OF PEOPLE WITH AN INTELLECTUAL DISABILITY

■ ACT   ■ NSW   ■ NT   ■ QLD   ■ VIC   ■ WA   ■ TAS   ■ SA

2%
1%
3%
13%
-1%
8%
7%
66%

AGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY

Family members

We received a total of 40 responses from family members during the survey period.

More than half of respondents were from Western Australia, followed by 18% from Tasmania. The majority of respondents were from cities or outer suburbs compared with 23.7% from regional areas. There were no respondents from rural areas.

This survey captured a similarly broad age range, between 15 years and 68 years, with 45% of respondents' family member being in their 20s.

94.9% of the respondents said their family member was a NDIS participant.

LOCATION OF FAMILY MEMBERS

■ ACT   ■ NSW   ■ NT   ■ QLD   ■ VIC   ■ WA   ■ TAS   ■ SA

AGE OF FAMILY MEMBERS WITH AN INTELLECTUAL DISABILITY