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Meaningful Work for People with Intellectual Disabilities

Final Report

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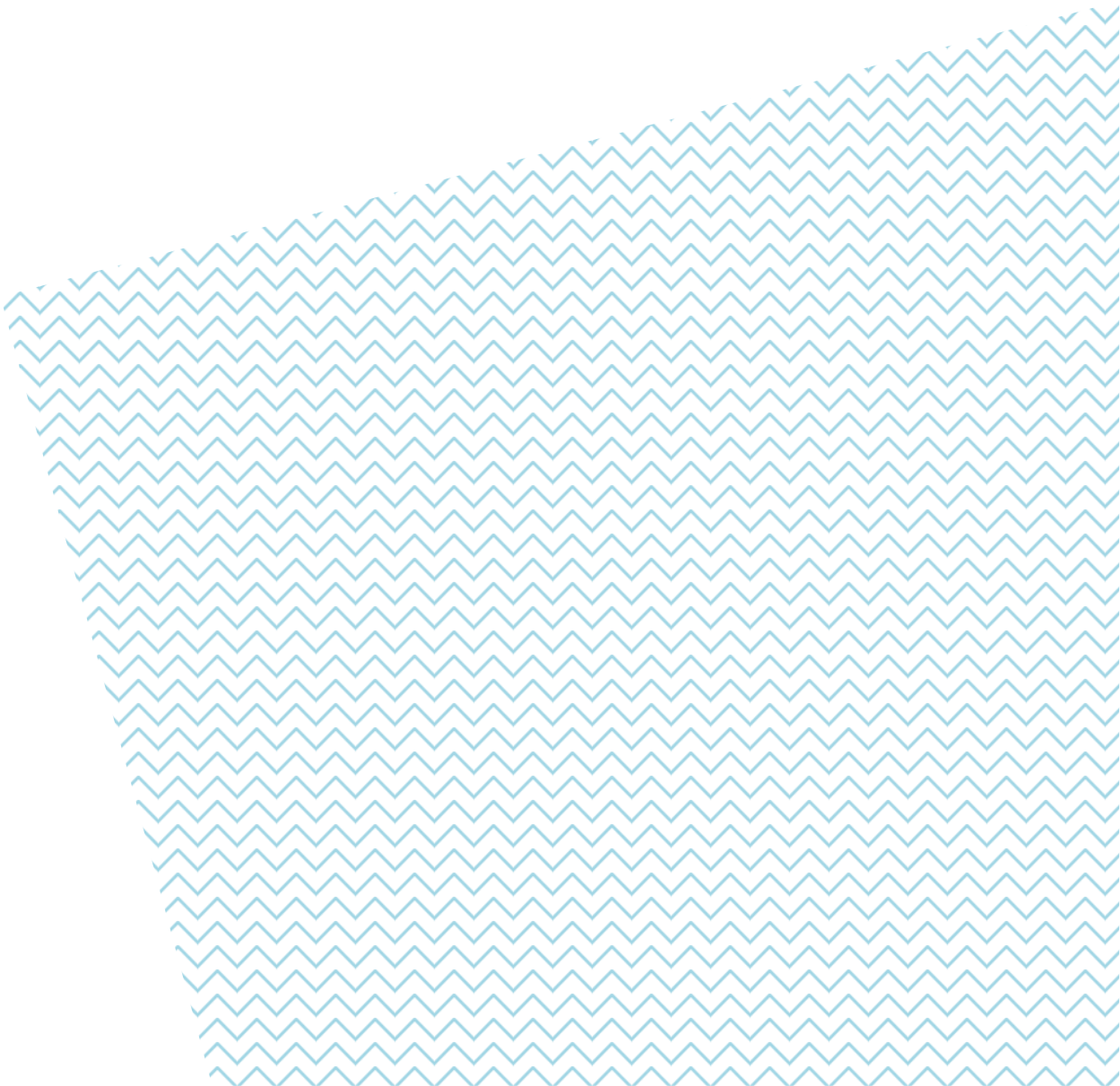

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Acknowledgments

Thank you to VALID for assisting in the recruitment of participants.

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Plain language summary

This report is about people with intellectual disabilities and the work they do.

It asks what makes work meaningful for them.

It also asks how more people with intellectual disabilities can find meaningful work.

To answer these questions we talked to 10 people with disabilities about their jobs.

We asked them:

- How did you find your job?
- What do you like about your job?
- What don't you like about your job?
- Does your job feel meaningful to you?

What did we find?

1. Getting work is hard.

People had to try very hard to find jobs.
Some gave out lots of resumes to businesses.
Family, friends and support workers were a big help.

2. Keeping work can be hard too.

Some people were given boring or unfair jobs.
Some people didn't get the help they needed to do their job.
Some felt left out by their co-workers.
Support workers and families helped make things better.

Some workplaces were flexible.
They let people choose the right hours or tasks.
This helped people enjoy their jobs more.

3. What is meaningful work for one person may be different for another.

Not everyone wants the same thing from a job.
The things that made work meaningful for most people were:

- They felt respected and treated the same as others

- They were paid fairly
- Their work helped other people
- They did work that the enjoyed
- They made friends at work

What should change so more people with intellectual disabilities find meaningful work?

- Jobs need to be flexible.
- Let people do the work they are good at.
- People with intellectual disabilities should be paid fairly for the work they do.
- Support people with intellectual disabilities to find and keep jobs.
- People with intellectual disabilities should be leaders.
  They should help plan and improve work places, because they know what makes a job meaningful.

Introduction

Despite decades of reforms and targeted initiatives, people with intellectual disabilities continue to experience barriers to securing and sustaining employment, particularly in the open labour market (Young & Rooney, 2023; Zhang, 2023). In Australia, only 32% of people with intellectual disabilities in working age were employed in 2018, significantly below the rate for the general population (80.3%), and for the wider population of people with disabilities (47.8%) (ABS, 2018).

Debates surrounding employment for people with intellectual disabilities are often focused on the question of whether 'non-mainstream' employment is a suitable alternative to mainstream work. Mainstream employment, variously termed open, competitive, or integrated employment, involves people with intellectual disabilities working in ordinary workplaces alongside people without disability. Non-mainstream employment includes specialist settings such as supported employment, sheltered workshops, and Australian Disability Enterprises (ADEs), designed primarily for employment of people with disabilities. While this binary has structured much of the conversation about what constitutes appropriate employment, it has also constrained thinking about what makes work valuable to people with intellectual disabilities themselves.

In this report we focus on the concept of meaningful employment as an alternative approach. Meaningful employment shifts attention away from the formal characteristics of a workplace as either mainstream or non-mainstream, instead asking how individuals can find and sustain work that provides benefits that they personally value. These benefits might include income and financial independence, a sense of purpose, opportunities for personal growth, social connection, or a sense of contribution (Rosdianti, 2017; Hall & Kramer, 2009; Andrews & Rose, 2010), but each individual might prioritise different benefits.

The report examines what people with intellectual disabilities consider to be ‘meaningful’ work, and to what extent their present or past experiences of work have felt meaningful to them. The remainder of the report is structured in three parts. First, we discuss the concept of ‘meaningful work’ drawing on previous studies on the varied potential benefits of employment for people with intellectual disabilities. Second, we review existing literature on the barriers that people with intellectual disabilities face in accessing employment and meaningful employment. Third, we present findings from our interviews with nine people with disabilities – including six with intellectual disabilities – about their experiences of finding and maintaining employment, and to what extent they have experienced that work as meaningful.

What is meaningful work?

Although the term ‘meaningful work’ is often used in the literature, it is rarely defined in precise terms. However, existing literature provides clear evidence on the different types of benefits that employment could potentially provide individuals. These include:

- **Financial independence and economic security**: Inadequate disability pensions, high costs of living, and additional disability-related expenses make paid work an essential path to financial stability (Australian Federation of Disability Organisations, 2011; Rosdianti, 2017).
- **Social connections**: Work can offer vital opportunities for interpersonal connection, inclusion in community life, and participation in broader social networks (Hall & Kramer, 2009; Commonwealth of Australia, 2023b).
- **Health and wellbeing**: Employment is associated with improved mental and physical health (Andrews & Rose, 2010; Commonwealth of Australia, 2023b).
- **A sense of purpose**: Having a rewarding occupation can give people a sense of identity, purpose and personal growth (Hall & Kramer, 2009; Gjertsen et al., 2021)
- **Skill development**: Work may foster new skills and confidence, supporting broader life goals and future opportunities (Stephens et al., 2005).

While these studies offer important insights about the kinds of benefits that work could provide, in this report we acknowledge that individuals can differ in the relative weight they place on each of these benefits, based on their personal values and aspirations. What make work meaningful can be different from one person to another.

Barriers to employment and meaningful work

Despite growing recognition of the benefits of employment, multiple barriers continue to limit people with intellectual disabilities' opportunities to enter employment, and even more so to enter and sustain *meaningful* employment opportunities.

Structural changes in the labour market, including the shift towards knowledge-intensive work, have increased the cognitive demands of many jobs, posing barriers for people with intellectual disabilities (Barnes, 2000). Attitudinal barriers including stigma and discriminatory hiring practices also remain widespread (Commonwealth of Australia, 2023a, p. 4; Reparon et al., 2024).

Taking up paid employment can lead to a loss of income support, and can deter people from actively seeking paid work, particularly in low-wage or insecure roles (Beyer et al., 2010; Andrews & Rose, 2010). Some individuals may also lack access to effective support to seek and apply for jobs, or employment services tailored to their needs (Commonwealth of Australia, 2023b).

Standard pathways into employment often prove ineffective for people with intellectual disabilities. Training programs may fail to equip individuals with the specific skills needed for a particular job. While "place-and-train" models, where individuals are supported in real work environments, have shown greater promise (Commonwealth of Australia, 2023b), such opportunities are still rare.

Even when people with intellectual disabilities enter employment, inadequate job matching, communication inaccessible technology, and poor support from employers can undermine the experience (Mittendorf, 2024; Reparon et al., 2024). These barriers are not just obstacles to employment, but obstacles to meaningful employment.

The difficulty to access mainstream employment means many people with intellectual (and other) disabilities often find work in non-mainstream employment, such as Australian Disability Enterprises (ADEs), where pay is below the minimum wage. People with disabilities sometimes feel forced to accept such roles due to limited mainstream alternatives (Trezzini et al., 2021). Research suggests that the experience of employment for people with intellectual disabilities in such settings is highly variable. Some studies highlight the risks associated with segregated employment, including low wages, poor working conditions, and heightened vulnerability to exploitation and abuse (Commonwealth of Australia, 2023b, 2023c). Yet some individuals value the familiarity, routine, and support provided in sheltered work settings, and report meaningful connections and satisfaction in these contexts (Blick et al., 2016). The prevalence of ADEs was identified as a significant issue in the 2023 Final Report presented by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. It recommended the phasing out of ADEs by 2036. This recommendation remains 'under consideration' by both federal and state governments, with no definitive commitment to implement the phase-out at this time.

In the following sections, we report on the findings from interviews with nine people with disabilities about their employment experiences. We examine the extent to which their experiences reflect what we have described above as meaningful employment, and identify barriers and enablers to finding and securing meaningful employment in their experience.

The study

This study was co-designed by Luke Nelson (LN) and Ilan Wiesel (IW). LN is a self-advocate with intellectual disability employed as a research assistant at the University of Melbourne, and IW is an academic in the same institution. The project began with an initial workshop to identify a research focus of shared interest, and we decided to investigate meaningful employment for people with intellectual disabilities.

From the outset, the research team chose not to restrict the study to open or mainstream employment. This decision was informed by recognition that some people with intellectual disabilities engage in unpaid or non-mainstream forms of work that they nonetheless find meaningful and valuable. It was decided to focus specifically on people with

intellectual disabilities, acknowledging that their experiences of employment can differ significantly from those of people with other types of disability.

The research plan was co-designed over a series of in-person and zoom workshops. These included the formulation of research aims and questions, the design of the recruitment strategy, and the development of the interview guide. Ethics approval was granted by the University of Melbourne Human Research Ethics Committee.

We sought to include in the study up to ten participants with an intellectual disabilities who have had experience of work that they valued. The aim was to identify not only barriers but also enablers of meaningful work for people with intellectual disabilities.

Participants were recruited through two main channels: via the Victorian advocacy organisation VALID, and through LN's personal and professional networks. Easy English information sheets were distributed through both channels to participants, inviting people with intellectual disabilities with work experience to participate in the study. Each participant received a $50 gift voucher in recognition of their time.

While the intention was to interview only people with intellectual disabilities, three of the nine participants who responded to the invitation had other types of disability, mostly physical. The decision was made to proceed with these three interviews, since they were already scheduled and participants had set aside time for the interview. Although this was not planned, the inclusion of participants with different types of disability offered useful points of comparison, helping to highlight the distinctive aspects of the employment experiences of people with intellectual disabilities. Six participants were men, and three women.

All but one interview was conducted remotely via Zoom. LN led the majority of interviews using the jointly developed interview guide, with follow-up questions asked as needed by IW. Three participants chose to have a support person, either a parent or a paid support worker, present during the interview. Interviews were recorded and auto-transcribed using Zoom's transcription tool.

Two additional researchers, Imogen Howe (IH) and Frances Grimshaw (FG), contributed to the project. IH supported the preparation of a review of the relevant literature, while FG assisted with analysis of the interview data. FG worked closely with LN in a collaborative data analysis process that involved identifying key themes across transcripts and interpreting the data through discussion and shared reflection. The next section outlines the key findings from the analysis, and is structured around three overarching themes identified through this process: 'getting work', 'making employment work', and 'meaningful work'.

Getting work

The process of gaining employment required participants and their supporters to navigate a web of challenges. The effort put in by participants to overcome these is a testament to the value they sought, and in some cases were able to fulfill, through work.

Participants faced significant challenges finding employment, and especially work they considered meaningful. Participants often faced rejection or silence from employers they approached. Some employers explicitly stated that they did not want to hire people with disabilities. Others showed initial willingness to offer work, but then quickly withdrew offers.

"Some employers will say, 'We don't want a person with a disability... they don't know much, and sometimes they can't do our jobs. So we don't want them" – Marcus

"Sometimes people will say yes to Daniel's face, and then they'll cancel it afterwards, which is a bit of a shame" – Daniel's support worker.

Participants criticised rigid hiring practices that prioritised inflexible criteria. Some expressed frustration at employers requiring formal qualifications rather than skills and experience, noting that opportunities for attaining formal qualifications were limited due to inaccessible professional and tertiary education institutions. Some participants felt that the requirement for formal qualifications reflected rigidity.

Despite these challenges, participants were able to find work, including meaningful work (noting that we intentionally selected participants who were already in meaningful work). Factors that enabled participants to find work included:

Support: Support from family members, support workers and the broader communities of friends and peers was essential in finding work opportunities. Supporters helped participants approach employers and negotiate the role. Aisha found most of her jobs through neighbours, disability agencies, and family friends. Marcus's support worker was essential in negotiating better conditions for him and helped him find courses to support further professional development. In another example, Leo's 3-hour shift on weekdays at a café was negotiated between him, support workers and his employer.

Champions within the workplace: success often hinged on encountering a manager or employer willing to take a chance, who was willing to do things differently. The risk is that when supportive managers or team members left, people can face new challenges in maintaining stability and inclusion.

Proactivity: Participants were proactive and creative in the ways they found work. Most participants found employment not through advertised job vacancies, but by proactively reaching out to potential employers—such as sending unsolicited emails or making direct contact. Some participants had handed out countless resumes. Dina, for example, would contact the local council with ideas for work, which led to volunteer opportunities and committee roles. Participants were willing to make some compromises to find a work that they considered meaningful, such as being willing to travel long distances to such work.

Making employment work

After securing a job, participants often faced challenges holding on to their positions and maintaining a sense of meaning and satisfaction in their work. Participants encountered discrimination within the workplace, tokenistic tasks, and felt their contributions were not valued. Many of these challenges stemmed from unreasonable productivity expectations or rigid top-down processes that limited adaptability.

For example, Brendan found a volunteer role working with animals, as he had hoped, but was disappointed with the role he was assigned:

"I wanted to volunteer to walk the dogs, but I didn't realise that the dogs that come to them are because of previous abuse... They were worried that they could tear my shoulder." - Brendan

The decision about what work Brendan could safely perform involved a lengthy bureaucratic process. Ultimately, he was assigned a different role which left him feeling that his time and abilities were undervalued.

In other cases, participants described lack of support in the workplace to carry out the tasks assigned to them. Marcus, for example, explained:

"If I ask for help, my boss says, 'You can do it by yourself.' But I sometimes do need help." - Marcus

Social isolation within the workplace was also a source of dissatisfaction. Marcus noted feeling left out socially, observing that while his colleagues were friendly with one another, they often excluded him from interactions.

Participants highlighted the financial challenges of staying in work, including the costs of additional coaching, which were critical for ongoing success in their roles.

Factors that enabled participants to maintain work included proactive negotiation of tasks; responsive and flexible approach on the side of managers; and availability of external support to manage difficulties.

Participants highlighted the importance of workplaces and managers open to conversations and to negotiating tasks and hours to align with individuals' skills and abilities, rather than forcing people to meet the requirements of predetermined job descriptions or leave. However, participants noted such flexibility could be rare. The process was often complicated by bureaucratic processes, making it challenging for people with disabilities to sustain positions they have found.

Support workers and families played a pivotal role in assisting participants negotiating arrangements with employers, advocating for flexibility, and ensuring roles were adapted to meet individual needs. Supporters were instrumental in resolving conflicts and fostering a culture of inclusion within workplaces. Practically, this often meant working with managers to create shortened shift times, finding tasks that were both appropriate and enjoyable, and advocating for participants when discrimination or misunderstandings occurred. In some cases, support workers had a hands-on role. For instance, Leo's support worker provided real-time guidance to help him perform his tasks independently, which contributed to his growing confidence and sense of belonging.

Meaningful work

Employment attracted participants for many reasons, including opportunities to get out of the house, form social connections, receive fair pay, make an impact on an issue they care about, and have fun. For participants, work provided a sense of identity, purpose, and connection to their communities. Being recognised and respected in their roles, through fair pay and opportunities to engage with the community, made participants feel valued and connected.

Social connection

Participants placed high importance on social connections within the workplace as significant part of what makes work meaningful to them. Being part of a team and collegiality with coworkers were key factors that contributed to their sense of meaning and satisfaction in their work. Feeling respected, valued, and included were consistently identified as important parts of their work lives.

Social connections were formed through work collaboration with co-workers. Daniel and Jackson both mentioned that teamwork was their favourite aspect of their jobs.

"It's very good to learn because you've got other workers helping each other and working together." Jackson

In some cases, employers proactively facilitated social connections for participants. Aisha's employer, for example, made sure she is included in workplace social events and celebrations. Participation in these events helped foster connections with people not just within the workplace, but also in the wider community.

Recognition and fair pay

Work felt meaningful to participants when they felt recognition of their contribution by their employer, colleagues, customers and the broader community.

Being paid fairly for their work was a significant aspect of 'meaningful' employment for some participants. Being paid on par with others reinforced the idea that their work was valued and that they were treated equally within the workplace. Emily, for example, emphasised, "My main thing is to get financially stable through a job that I love doing, and I believe that any job should be paid for". Emily expressed frustration with roles that relied heavily on volunteers, noting that while volunteering provided initial fulfilment, it ultimately failed to support financial stability and independence. However, some participants were paid at a lesser rate (between $10-20 dollars an hour) or volunteered and still found their work meaningful for other reasons, such as social connections and making a positive impact in the world.

Beyond pay, being recognised as capable, respected and valued worker by employers, other colleagues and members of the community was important for many participants.

That he's a valued member of the team, and he's a mate, you know, and all that stuff." – Leo's parent

Being held to the Same standards as other employees, was described by Aisha as a form or recognition and respect:

"They kind of hold you to the same standard as the other employees, which I really like... They don't treat you different. You're really the same." – Aisha's support

Recognition was sometimes expressed through small gestures, such as being greeted by co-workers. Leo's supporter highlighted the respect and acknowledgment he received at work: "Leo is doing it mostly independently most of the time. And just how he's being treated there, you've got people from other departments who would greet him outside of work."

Daniel's carer noticed that when Daniel wore a uniform, people would be friendlier to him and treat him with respect. A few participants talked about how having a suit and tie job would be a dream for them, to be seen as an urban professional.

Making a positive impact

Participants frequently emphasised how their work provided opportunities to support others and contribute to their communities, either through the work itself or through showing up with a disability in a public space.

Several participants were engaged in disability advocacy and policy work cited social justice and change as things that made their work meaningful. This was reflected more strongly in the interviews with participants with a physical rather than intellectual disability: Craig, Emily and Dina. Craig reflected, "Everything I do is really based on influence and creating positive change for the community. I feel very invigorated and fulfilled when I know that I'm influencing others and getting outcomes that are going to lead to people having better lives". Dina highlighted the value of her advocacy work, stating that helping others navigate barriers to inclusion made her feel "worthy even with what is occurring and has occurred to me". Emily articulated a similar sentiment, sharing her desire for her consultancy work to "actually make a legit difference" and contribute meaningfully to the communities she served.

Participants with intellectual disabilities also sought a sense of purpose in their work, but expressed it differently. For example, Brendan's desire to work with animals reflected a different sense of purpose he sought in his work.

Conclusion

Participants' strong desire to work and contribute meaningfully is a powerful reminder of the value they place on employment, and of the untapped potential that remains overlooked in current systems. The study examined what participants value most in work. Participants sought social connection, a sense of purpose and recognition, and fair pay. Because of their exclusion in the workforce, some people were forced to make unfair compromises, for example to give up on fair pay, so that they can experience other benefits of employment such as a sense of purpose and social connections.

The research revealed that entry into employment often depends on informal networks, proactive efforts, the advocacy of supporters and flexibility of employers. These findings affirm that with the right support from formal and informal support providers as well as employers, people with intellectual disabilities are able to find and maintain meaningful work.

Even once work is secured, maintaining a sense of meaning in the workplace depends on flexible job design, and the flexible and positive attitudes of co-workers and employers. Many of the challenges participants faced, including rigid systems, lack of support, and low expectations, reflect broader structural inequalities.

Three implications for policy directly arise from the findings of this report, as pathways to expand opportunities for meaningful employment by people with intellectual disabilities, adding to exiting literature in the field.

Firstly, flexibility emerged as a key principle of inclusive employment for people with intellectual disabilities. Programs that encourage and support employers to adapt roles to individuals' skills and needs, rather than requiring workers to conform to inflexible job description, will promote inclusive recruitment and retention practices.

Secondly, the findings highlight the critical role of families, support workers, and informal networks in helping people with intellectual disabilities to find and sustain meaningful work. There is a need for public investment in resources and training for supporters, and foster connections between employment services and communities.

Thirdly, the research process and the findings highlight the value of involving people with intellectual disabilities as co-designers, advisors, and evaluators in employment initiatives, recognising their expertise in what makes work meaningful.

The phasing out of segregated employment is a necessary step toward greater inclusion, but it is crucial that mainstream employment settings adapt to accommodate the diverse abilities of people with intellectual disabilities.

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