Achieving a 'sense of purpose': pathways to employment for NDIS participants with intellectual disability, on the autism spectrum and/with psychosocial disability

SUMMARY REPORT

Research and Evaluation Branch – Policy, Advice and Research Division

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About the Research and Evaluation Branch

The Research and Evaluation Branch is responsible for ensuring that the work of the NDIA is informed by high quality evidence. Our works helps the Agency to understand what works, what doesn't work, and the benefit to participants and the Agency.

This document

This report presents research findings from the Employment Research Project.

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Abbreviations

Abbreviation	Term
ADE	Australian Disability Enterprise
CALD	Culturally and Linguistically Diverse
DES	Disability Employment Service
HSC	High School Certificate
LAC	Local Area Coordinator
LGBTIQA+	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, Asexual and + to represent the many more identities and affirmed genders
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
PitC	Partner in the Community
SLES	School Leavers Employment Support
SME	Subject Matter Experts

Glossary

Term	Definition
Autism spectrum*	This term refers to a group of neurological disorders that are characterised by impairments in social interaction, communication, repetitive behaviours, and restrictive interests. Impairments can vary widely between people and may change over a lifetime.
Intellectual disability	Is a term used to describe a range of conditions that impair general mental abilities including intellectual functioning (such as learning), and adaptive functioning (such as communication and living independently).
NDIS participants	When referred to in the findings includes NDIS participants, family, carers and other supporters who spoke to the participant experience.
NDIS service delivery staff	Includes NDIS planners, delegates, Local Area Coordinators (LACs), Subject Matter Experts (SMEs), and Partners in the Community (PiTC).
Paid employment	Work that is paid, including at a subsidised rate.
Person-centred supports and services	Person-centred supports and services are based on putting the person at the center of the decision, resulting in supports that are individualised to the person.
Psychosocial disability	Psychosocial disability is a term used to describe a disability that may arise from mental health issues.
Research participant	A research participant is a person who participates in the research.
Survey respondent	A survey respondent is someone who has filled in a survey.

*People prefer different terms to describe autism. To acknowledge this, we use the terms autism spectrum and participant on the autism spectrum in this report. We have used person first language to be consistent with how we refer to the other target populations. However, we acknowledge the contested nature of 'person first' and 'identity' language.

Background

People with disabilities have the same right to access employment opportunities as the rest of the population (UN General Assembly 2006, Article 27). The Agency is committed to supporting participants who want to start thinking about work or need support to do well in their job.

To ensure that National Disability Insurance Scheme (NDIS) participants have the necessary supports they need to find and keep a job the National Disability Insurance Agency (NDIA) launched the NDIS Participant Employment Strategy (2019-2022). The primary goal of the strategy is to have 30 per cent of NDIS participants of working age in paid work by 30 June 2023. This Strategy outlines a series of activities that the NDIS will undertake to help remove barriers to employment for people with disabilities. These activities will help NDIS participants to set and work toward employment goals.

Why we did this research

Approximately two-thirds of NDIS participants have intellectual disability, on the autism spectrum, and/or with psychosocial disability.

We need to understanding what helps or makes it harder for participants to find and keep a job and plan a career. This will help the NDIA to support participants who want to work.

By doing this research, we wanted to:

- Find out about participants' experiences and the pathways to paid employment,

- Explore what makes it easier or harder to find and keep a job,

- Identify the information and supports participants need (including families, carers or supporters) to help them develop employment goals and get ready for work.

The research presented in this report is part of a larger research program that includes:

1. An **evidence review** of 161 published articles and reports. The review identifies what interventions work to improve employment outcomes for people with intellectual disability, on the autism spectrum, and/or psychosocial disability. The review was commissioned by the NDIA and was undertaken by the University of Melbourne in collaboration with the University of NSW and the Brotherhood of St Laurence.
2. A **data analysis report** using NDIS participant outcomes data to identify factors associated with finding or keeping a job.

To read the Employment Outcomes Report, visit the NDIS Data and Insights website.

To read more about our research findings, visit Research and Evaluation on the NDIS website.

Paige, NDIS participant, intellectual disability cohort, aged 20 years

"I think having fun and enjoying the job that you're doing is really important. I also think that if it's a job that you're already passionate about or that you thought about it, it's good for the job and good for you to have a really fun experience."

What approach did we take for this research project?

Our research approach included in-depth interviews with NDIS participants (families, carers or supporters) aged 14 to 44 years.

We aimed to talk to 80-100 participants to help reach data saturation on themes and topics (i.e. no new themes arises from the data).

Three NDIS participants worked with us to make sure research methods, research tools (e.g. interview questions), and findings were relevant for NDIS participants in the three disability cohorts.

We spoke to participants in different ways including video online, telephone, or email. Participants heard about this research via the NDIS Participant Engagement Group, NDIA website, peak bodies, social media and other organisations.

We also spoke to NDIS service delivery staff which included planners or delegates, Local Area Coordinators (LACs), and Subject Matter Experts (SMEs). We did this via video online. We also invited staff to participate in an online survey.

This research project was funded by the NDIA and approved by Monash Health Human Ethics Committee (RES-20-0000-276A).

Who took part?

Eighty-five NDIS participants or family, carers, and other supporters participated in interviews. These lasted up to an hour. This included:

• 39 NDIS participants

• 46 family, carers, and other supporters

Some parents spoke about more than one child. Sometimes we spoke to both the person with disability and their carer. So a total of 86 NDIS participants aged between 7 and 44 years were included in the research:

• Autism spectrum (n=30),

• Intellectual disability or Down syndrome (n=35),

• Psychosocial disability (n=21).

Focus groups and interviews were held with LACs (n=21), planners (n=10) and other staff (n=6). There were 142 responses to the online survey (71 LACs/PiTC, 62 planners or delegates and 9 employment SMEs). Respondents were from across Australia and had different experiences with work.

Lady Nova, mother of Starkid, autism spectrum cohort, aged 17 years

"He worked in a very small retail situation in the back room of a computer repair shop. So he was working with a fellow who owned the business who has ADHD and some autistic traits, so he understood what Starkid was going through. He was a great role model and saying, "You know, I've got issues too mate. You can do this. This is fine. Keep going. You're doing well". So he knew exactly how to manage some of Starkid's behaviours and fears so that was awesome".

What did the research find?

Employment was important to participants

Participants reported that having a job increased their connections with other people and "gave them a sense of purpose". Participants told us that having a paid job made them feel proud, challenged and enthusiastic. They told us work that was meaningful was important. Having work colleagues that are welcoming and supportive was also important.

Participants told us they found work through:

- Government and non-Government funded employment services
- Work experience or work placements
- Participating in their community through clubs and groups or volunteering
- Their own or their family's networks

Barriers and enablers to finding and keeping a job

Participants told us what made it easier or harder to find or keep a job. We have grouped what participants told us into five groups:

1. Common experiences for all participants
2. Experiences of young people and school leavers
3. Experiences of participants returning to work
4. Keeping and changing jobs
5. System barriers to finding and keeping a job

Common experiences for all participants

Both participants and NDIA staff reported lack of inclusive employment options as the greatest barrier to participants finding and keeping a job.

Participants told us what made it easier or harder to find work. They said:

- Staff and supporters did not always understand their disability well. Planning that puts the needs of the person at the centre (person-centred planning) is important to help participants to work towards a job that is matched to their skills and interests.

- Having supports to meet base level needs (such as daily living, stable accommodation, mental and physical health) gave them the energy and time to find and keep a job or work on their career.

- A lack of self-confidence made it hard for participants to see themselves as an employable person. Supports to build a person's skills and confidence is important. Families and a person's own networks can also help participants build their self-confidence. Personal networks also helped participants with their work and career goals.

- It was difficult to know what employment supports were available and how to access them. Having clear, consistent and accessible information and resources could help participants to understand what services were responsible for employment support and what evidence-based supports are available.

- There was a lack of appropriate transport options. This restricted participants' access to workplaces. Travel training or supporting participants to gain a driver's licence can help them to find and keep work.

Experiences of young people and school leavers

School leaver participants and their family, carers and supporters told us what made it easier or harder to find a job. They said:

- Schools play an important role in identifying the skills and interests of younger people. They can also help them to identify relevant employment options. Early discussions and planning with families was important to identify future job and career pathways (e.g. pre-high and high school discussions).

- Personal informal networks supported participants to find, and have a positive experience, in their first job. Role models, such as peers, family, and people in the media, helped them to find the options available, show what is possible and change community, and employer, attitudes about disability.

- Work experience was an important pathway to employment. However, knowing what NDIS funding was available to support work experience while participants are at school was difficult to find and confusing. It was also hard to know how and when they can access School Leaver Employment Supports (SLES) and employment supports.

- Post-school education and training was seen as a way to build skills and work towards getting a job. But there is a lack of options available for people with an intellectual disability or autism.

Experiences of participants returning to work

Participants looking for a job after a break in employment faced many of the same barriers as those identified above. These barriers were greater due to being out of work for long amounts of time. They told us what makes it easier or harder to find a job after some time out of work. They said:

- That having the NDIS and funded supports has been a positive step towards re-entering work.

- Long periods of unemployment made it harder to return to work due to looking unfavourable to potential employers.

- Stretches without a job meant they needed to rebuild their employment skills. But staff sometimes had difficulty knowing where to refer them.

- Retraining and returning to further education was a way to work towards getting a job that matched their skills and interests.

Keeping and changing jobs

Participants currently or previously employed told us what helped or made it harder to stay in a job.

They told us:

- Flexibility in support levels (such as travel training and support workers in the workplace) helped them to increase or decrease supports, as they needed.

- Workplace flexibility supported participants to stay in employment but this needed to be individualised.

Participants with psychosocial disability or on the autism spectrum told us:

- Stigma and discrimination associated with their disability made it hard to stay in employment.
- Telling colleagues or bosses about their disability could lead to either discrimination or more workplace supports.
- Informal (e.g. family or friends) and formal supports provided advice, support, and encouragement when they experienced or perceived stigma and discrimination.

System barriers to finding and keeping a job

Participants told us about times when employment services or supports acted as blockers or barriers to gaining employment. While not within the responsibility of the NDIA. They said:

- Being with Disability Employment Services (DES) providers for years without success made it hard to find work. Some participants reported DES providers often had a lack of knowledge of disability beyond physical disability.

- Sometimes Australian Disability Enterprise (ADEs) were the only option presented to them. Some participants working at ADEs enjoyed their work and the friendships they made while others said that they would like the opportunity to participate in capacity building opportunities that may not be available through their ADE provider.

- They were worried about having a job and being paid enough and losing the Disability Support Pension (DSP). They want to earn a living independent of government payments, but it was hard to earn enough from a job. Clearer information about the DSP would help reduce the confusion and worry that participant had about the DSP and how it works when you get a job.

Key findings from what service delivery staff told us

We asked NDIS service delivery staff (LACs, Planners and employment Subject Matter Experts) what they thought made it harder or easier for participants to find and keep work. Out of a list of 14 things that may make it harder (barriers) for participants to find work. They said:

- A 'lack of person-centred or individualised supports to find work' and a 'lack of inclusive employers' were ranked the greatest barriers for all three disability cohorts.

Out of a list of 18 things that may make it easier for participants to find work. They said:

- 'Ongoing support and job readiness training' was ranked the greatest enabler to improving employment outcomes for all three disability groups.

Alexis, psychosocial disability cohort, aged 44 years

'I guess for me, it's been about improving myself to move into a better position. Because after being hurt at work, I didn't want to just get some basic checkout chick job and feel like bad about myself. I actually wanted to see my time off as somewhere where I could improve. And that's why I went back to university and ultimately moving into a different area that I actually have an interest"

What next?

The findings from this research project alongside an [evidence review](#) and the [employment outcomes report](#) will inform the Agency's targeted approach to delivering the Participant Employment Strategy in 2021-2022 and will continue to do so. The research will also be used to develop participant-facing resources to support participants to implement their plan and resources for front-line staff to use in conversations with participants to help them find and keep a job.

We will use this research to develop useful resources for participants and staff that can help them have conversations about finding and keeping a job and the types of support that can assist.