



Effectiveness of the National Disability Insurance Agency's management of assistance with daily life supports

Submission to the Australian National Audit Office

About us

Inclusion Australia is the national Disability Representative Organisation representing the rights and interests of Australians with an intellectual disability and their families.

We have state members in New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia:

- Council for Intellectual Disability (CID)
- Parent to Parent (P2P)
- South Australian Council on Intellectual Disability (SACID)
- Speak Out Association of Tasmania (Speak Out)
- Victorian Advocacy League for Individuals with Disability (VALID), and
- Developmental Disability WA (DDWA)

Inclusion Australia was founded in 1954 and was previously known as the National Council on Intellectual Disability (NCID). Our mission is to work to make sure people with intellectual disability have the same opportunities as people without disability.

Inclusion Australia works in systemic advocacy, projects, information and communication activities that advance the rights and interests of people with intellectual disability.

The National Disability Insurance Scheme

People with an intellectual disability and their families will likely use disability support services for their entire lives, giving them considerable expertise about how these support systems function and how to improve them. They make up about a third of people with disability who use National Disability Insurance Scheme (NDIS) supports, including Supported Independent Living funding.

The NDIS is the biggest service system for people with an intellectual disability, and it also influences other systems that people engage with. As such, we want to see the NDIS to operate with a high level of respect for, and understanding of, people with an intellectual disability and their families, and their experiences.

People with an intellectual disability and their families want to see changes to how the NDIS operates in three key areas. These are:

- Supported decision-making
- Being included the community
- Complexity.

What do people with an intellectual disability say?

Inclusion Australia's Our Voice Committee, a subcommittee of our board comprising people with an intellectual disability from across Australia, have consulted with other people with an intellectual disability about the NDIS.

Our Voice heard that there were elements that were working well with people's NDIS supports. These included:

- Getting enough support, more support hours, support at work, support to do more activities, support they hadn't had before.
- Being more independent, funding for transport, being listened to during planning meetings, moving out of home.

They also heard what wasn't working. This included:

- Funding cuts, a focus on money and budgets instead of what people need.
- Lack of consistency with what is funded, and what is refused, hard to understand decisions.
- Really complicated, lots of bureaucracy, staff turnover.
- Support workers treating people badly, not trained.
- Hard to access, reports cost huge amount.
- Hard to get good support coordination, LACs don't listen, need independent help.
- The NDIS is very stressful and complicated.

People had lots of ideas about what needed to change. These included:

- Easier information.
- Listen to us.
- Respect us.
- Stop funding cuts.
- Better support for people in rural areas.
- More help finding jobs.

Supported decision making

People with an intellectual disability often do not have a say about their lives, including about the NDIS disability supports that they use. For many people with an intellectual disability, someone else makes decisions for them, including under formal mechanisms like guardianship or as a nominee under the NDIS. This is known as substitute decision making.

Inclusion Australia, along with many other disability advocacy organisations, supports the right of people with an intellectual disability to have a say about what happens to them. People with disabilities have rights to make their own decisions. This is covered by Article 3, Article 4 and Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)¹. This is known as supported decision making (SDM).

The NDIS promises that people with disability will have access to person-centred disability supports that are individually tailored to their needs. This is not how the NDIS works for many people with an intellectual disability who do not have a say about their supports.

Australia has signed the UNCRPD and the Australian Law Reform Commission (ALRC) has suggested ways² to make these rights part of Australian law, including recommending key principles.

In 2021, the National Disability Insurance Agency (NDIA) undertook a consultation process to explore how they could implement supported decision making across the Agency and Scheme. Inclusion Australia provide a highly detailed and comprehensive submission, with many of the recommendations remaining current.³

In our submission, people with intellectual disability commented that it was good to see the NDIA wants to have support for decision making in participants' NDIS plans. They thought the NDIA made some good points about the rights of decision makers. People with intellectual disability liked that the consultation talked about people with disability making their own decisions and having support when they need it. They liked that decision supporters would have information about how to support decision making.

People also have the right to change their mind. One supporter has shared a story with us about people with intellectual disability changing their mind and having that used against them as proof that they are unable to make decisions. NDIS supports are often so rigid that NDIS participants cannot change their mind about the most mundane decisions in life. As one supporter put it:

“A lot goes on in a year... I might not want a shower in the morning anymore, I might want a shower at night, or I might want two showers a day! It's ridiculous that you can't get that.”

¹ “Convention on the Rights of Persons with Disabilities,” OHCHR, <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>.

² ALRC, “Towards Supported Decision-Making in Australia,” September 18 2014, <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/1-executive-summary-2/towards-supported-decision-making-in-australia/>.

³ <https://www.inclusionaustralia.org.au/submission/submission-to-the-ndia-on-support-for-decision-making/>

People with an intellectual disability with complex communication support needs require ongoing capacity building opportunities to develop the different ways that they communicate – through their natural language as well as through the use of alternative and augmentative communication strategies. It is essential too, that people with complex communication support needs, regardless of their age, receive ongoing capacity building to develop the skills of their paid and informal support people in observing, recognising, understanding and supporting the continued development of the person’s expressive communication.

Researchers have recommended that “Some form of mandated supported decision making and an explicit onus on NDIS staff to enquire into the nature of the decision support would help to set expectations about the quality of informal support, build the capacity of decision supporters for a rights-based approach, and provide criteria to assist in accountability of their practice. Such measures will be important in increasing the chances of adults with intellectual disabilities in realising the Scheme objectives of greater choice and control.”⁴

To date, we are not confident that the NDIA understands this, or is willing to put in place the key requirements to ensure that a person with an intellectual disability’s right to make decisions about their lives is upheld.

Since this consultation process, Inclusion Australia has been engaged by the NDIA to deliver further consultation via its Participant Engagement Panel, talking with groups of people with disability who require support for decision making and have significant barriers to accessing the NDIS. These groups include people with an intellectual disability from culturally diverse backgrounds, First Nations people with an intellectual disability, and people with complex communication needs.

We have provided comprehensive reports to the NDIA and we strongly urge them to take up the reforms that people with disability have asked for, including the implementation of a comprehensive supported decision making framework and the adoption of the ALRC principles.

In particular, support for decision making for people with disability must be independent from service providers, and other NDIS roles, such as Local Area Coordinators, but each of these roles need to understand and use the principles of supported decision-making in their work.

The NDIA has an opportunity to set a benchmark for how it engages with people with an intellectual disability and other people with disability who need support for decision making. If the NDIS is a person-centred Scheme, then support for decision making must be embedded in all NDIA practices and policies, such as planning, choosing supports and reviews, including in the NDIS Quality and Safeguards Commission.

The Commission plays an important role in regulation of the NDIS, including of disability support providers and disability support workers. They administer provider and worker registration and investigate complaints about violence and abuse of people with disability.

⁴ Christine Bigby, “Dedifferentiation and People with Intellectual Disabilities in the Australian National Disability Insurance Scheme: Bringing Research, Politics and Policy Together,” *Journal of Intellectual & Developmental Disability* 45, no. 4 (June 24, 2020): 309–19, <https://doi.org/10.3109/13668250.2020.1776852>.

Currently, the Commission has some discussion of supported decision making in the Code of Conduct that all providers and workers must abide by. The Commission says that:

NDIS providers should encourage workers to engage directly with people on any choices or decisions that affect them. They should consult them about who, if anyone, they want to involve in decisions and discussions about their services and supports, or other aspects of their lives.⁵

In our view this is inadequate. It does not accurately reflect Australia's human rights obligations as it 'encourages' rather than requires workers or providers to adopt supported decision-making practice. There is considerable opportunity for the NDIS Commission to share information with providers and workers about evidence-based supported decision making and the impact it has for participants' safety and the quality of the services they receive.

The Commission needs to invest in training models specifically about supported decision making, developed by and with people with an intellectual disability and people with complex communication needs, to build a shared understanding of what supported decision making is, and how it can be embedded in everyday practice.

Recommendations:

- The NDIA adopts a supported decision-making framework across all aspects of the Scheme and implements robust monitoring and evaluation to observe its uptake.
- The NDIA adopts the recommendations outlined in Inclusion Australia's support for decision making submission.
- Independent support for decision making is made available for all people with an intellectual disability using the NDIS.
- The NDIS Quality and Safeguards Commission mandates the use of supported decision making in their Code of Conduct, and provides specific disability-led training material.

⁵ <https://www.ndiscommission.gov.au/about/ndis-code-conduct>

Being in the community

The National Disability Insurance Scheme was built to deliver individual supports for the individual needs of each person with disability, but that is often not the case for people with an intellectual disability.

Group funding models across transport, daily activities, recreation, employment, housing and more are used predominantly to support people with an intellectual disability, instead of the individual supports available for other people with disability.

This group funding model locks people with an intellectual disability into activities and supports that others choose for them, rather than those they choose for themselves. This is significantly at odds with the choice and control that is meant to be at the heart of the NDIS.

Group funding also happens in specific and separate disability services, rather than in mainstream community services and supports. This reinforces the segregation from the community that many people with an intellectual disability experience.

The 2019 report from the NDIS⁶ about people with an intellectual disability shows that they are not having the same experience in the Scheme as other people with disability. Fewer people with an intellectual disability get to choose what they do each day than other people with disability, participate in a community activity, or are in education or learning a skill. While the statistics show that more people with an intellectual disability are in paid work, the majority of them are work in Australian Disability Enterprises, also known as sheltered workshops, for sub-minimum wages.

This snapshot, now three years old, gives a glimpse into the key differences in experiences of the NDIS between people with an intellectual disability and other people with disability. In addition, there are also significant emerging differences between younger and older people with an intellectual disability.

These differences are about how included people with an intellectual disability are in the community, and how often people go to separate schools, work in separate places and live in separate houses, often with other people with an intellectual disability and away from the community.

This separate world for people with an intellectual disability, particularly older people, has not changed with the introduction of the NDIS. Instead, group funding models have embedded and grown this separate disability-specific environment that is very different to the experiences of other people with disability who use NDIS supports.

The NDIA has reinforced this expectation about how people with an intellectual disability live, work and learn, instead of working hard to ensure people are fully included in the community.

People with an intellectual disability and their families are presented with group funding supports at their planning meetings, and not told that there are other options. Families tell Inclusion Australia that they are pushed towards these models of funding as though that is

⁶ <https://data.ndis.gov.au/reports-and-analyses/participant-groups/people-intellectual-disability-ndis>

all that people with an intellectual disability should expect or want. This is unacceptable. The NDIS must support full choice and control for people with an intellectual disability.

At a number of Disability Royal Commission public hearings⁷, disability service providers have given evidence about how people with an intellectual disability who live in their group homes go to work in their ADEs and use daily supports provided by the same service provider. This is known as service capture and is a common experience, especially for older people with an intellectual disability.

Service capture means that people with an intellectual disability often have no independent avenues of support, little choice or control over their supports, and few places to go if there is a problem, or if they experience violence or abuse.

There is a significant research gap about the impact and effectiveness of these group funding supports and service capture on the lives of people with an intellectual disability.

Supported Independent Living

Supported Independent Living (SIL) is funding to support people with disability with high support needs, and is used to support people with an intellectual disability who live in group homes rather than in the community.

Some people with an intellectual disability moved from large residential centres to group homes, and this transition to the NDIS has been life changing. One supporter described the changes she saw in the initial transition to SIL: 'increased community participation, increased choice and control, a lot of people reunifying with family members they hadn't seen in a long time because there was a reduction in the expectation around community access. There was more flexibility in the NDIS space for people to pursue their own interests as an individual'.

Unfortunately, Inclusion Australia has also heard many more stories about how SIL had the opposite effect on choice and control.

Advocates and supporters of people with intellectual disability often called SIL arrangements the 'last resort'. SIL is often the only option presented to people with high support needs – it is simply not a choice. This is especially true for people who do not have a broader support network or advocate to broaden their options. It is also common for younger people with disability coming out of hospital and aged care settings to be placed in SIL.

When first placed in SIL, a person may be given some choice and control in setting up their roster of care and putting support processes in place. However, when it comes time for renewal, the SIL assessment team rarely approves changes and asks for documented evidence on even minor adjustments.

Funding shortfalls in SIL can be incredibly difficult for participants, families and providers. For example, a participant who has complex support needs and requires some restrictive practices is currently going through the Administrative Appeals Tribunal (AAT) to seek more

⁷ DRC Public Hearings 13, 20, 23 - <https://disability.royalcommission.gov.au/public-hearings/our-public-hearings>

funding in his SIL package. His support team have documented five years of evidence to substantiate the level of support, however the NDIA still has not approved it.

People with disability who previously had successful housing arrangements have had their choice and control torn away by SIL practices.

There are currently reforms happening to the NDIS Home and Living policies to ensure that more people with disability can have a say about where and with who they live. These are vital for people with an intellectual disability, and closely linked to work on support for decision making. We advocate for a co-design approach to be taken to the reform process to ensure it is relevant to the real lives of diverse people with an intellectual disability, including those with complex needs, and that it is fit for purpose.

Recommendations:

- Independent support for decision making is available for all people with disability who live in SIL accommodation.
- Group funding is phased out for all people who use NDIS supports.
- Mainstream services are utilised more for people with an intellectual disability.
- The National Disability Research Partnership encourages research into impact of group funding models and service capture on the lives of people with an intellectual disability.
- SIL is used for innovative and different home and living options that deliver choice and control.

System complexity

People with an intellectual disability and their families tell Inclusion Australia every day about the huge administrative load they face in trying to get the support they need, particularly from the NDIS.

People with an intellectual disability and their families are navigating multiple state, territory and federal government systems and agencies, which often have multiple and conflicting eligibility criteria and program rules. These include:

- Disability Employment Services (DES)
- Centrelink and the Disability Support Pension (DSP)
- National Disability Insurance Scheme (NDIS)
- Education systems
- Housing
- Health and Medicare

Research for Inclusion Australia from Swinburne University finds this complexity is a barrier for people with an intellectual disability and their families, including to employment.⁸

There is consistent reference in the research from multiple countries, and in Australia, to the problem of the complexity of the disability, employment and education systems⁹. This creates difficulties for people with disability, their families and also for service providers in navigating this complex landscape, for which there is “currently no guide”¹⁰. International research has highlighted concerns, echoed by Australian research¹¹, in regard to:

the difficulty students and their parents face navigating services across different programs during the transition to adult life, limited coordination across agencies, and a lack of information about the full range of service options available to young adults with disabilities¹².

This complexity can lead to the polished pathway.

The polished pathway

People with an intellectual disability and their families often experience what we call the polished pathway into a lifetime of exclusion from the community. The complexity of the

⁸ Erin Wilson and Robert Campaign, “Fostering employment for people with intellectual disability: the evidence to date,” 2020, Centre for Social Impact, Swinburne University of Technology, <https://www.everyonecanwork.org.au/resources/evidence/>.

⁹ ACIL Allen Consulting, “National Disability Coordination Officer Program Evaluation,” 2017, https://docs.education.gov.au/system/files/doc/other/ndco_evaluation_final_report.pdf; K.-R. Foley et al., “Functioning and Post-School Transition Outcomes for Young People with Down Syndrome,” *Child: Care, Health and Development*, January 7, 2013, <https://doi.org/10.1111/cch.12019>.

¹⁰ ACIL Allen Consulting, “National Disability Coordination Officer Program Evaluation,” 2017, https://docs.education.gov.au/system/files/doc/other/ndco_evaluation_final_report.pdf.

¹¹ As above

¹² Allison Cohen Hall et al., “Building an Evidence-Based, Holistic Approach to Advancing Integrated Employment,” *Research and Practice for Persons with Severe Disabilities* 43, no. 3 (July 19, 2018): 207–18, <https://doi.org/10.1177/1540796918787503>.

support system, and the pressures on families to manage the enormous competing time pressures of work and care, can make real choice and inclusion very difficult.

For the families of people with an intellectual disability, the polished pathway is one that starts with small decisions in childhood. Families make what feel like ‘safe’ parental choices during those early tricky school years when everything feels overwhelming and tiring. Families are not told about the long-term implications of these ‘choices’, and are often presented with only one real choice.

Families are told in early childhood intervention: “Your child will never cope in mainstream school, and they will never cope with her”, so they “choose” special school.

Over the next few years, the advantages of this separate system, like dedicated transport and specialised holiday programs makes it easier to stay, as they take the administrative and care work from families.

In high school generally the only employment information students with an intellectual disability and their families are given is about Australian Disability Enterprises (or ADEs), a form of separate work with very low pay. Career planning supports for students with disability are limited. Fewer than one in five students with disability represented in a 2019 survey by peak body CYDA reported receiving assistance in understanding their strengths and skills for the post-school transition.¹³ Independent information about a wide range of available choices and supports is typically not available, and navigating those choices and supports is very difficult.

Work experience opportunities are not provided in the same way as for non-disabled students in mainstream schools.¹⁴ Instead, for many students with disability, in Year 10, the special school helpfully arranges group work experience at a local ADE – a fun time that includes organised group transport and a picnic. Students with an intellectual disability are not offered work experience or after schoolwork in mainstream employment in the same way as other students.

During Year 12, the school holds an expo for all the local ADE and day program providers.

People with an intellectual disability and their families find out that signing up means a smooth transition from school.

These exclusionary support options, that ease the complex administrative burden on families, also can protect the employment of families. This must not be the choice any longer.

This pathway is an incremental journey. The problem is it leads to people with an intellectual disability in poorly paid, segregated, and congregated ‘work’. It is shaped by low community expectations and supported by interlinking systems.

The connections between these systems, from early childhood intervention to Centrelink, from the NDIS to DES, and especially from school to work, are so smooth that families don’t even see they are heading towards this predetermined destination until the last minute.

¹³ CYDA, “Submission to the review of senior secondary pathways into work, further education and training”, 2020, <https://www.cyda.org.au/resources/details/64/the-review-of-senior-secondary-pathways-into-work-further-education-and-training>.

¹⁴ As above.

For people with an intellectual disability, once they are in these support systems, they don't leave. They will not enter mainstream employment or live in the community or have the same kinds of choices and experiences as other people with disability or non-disabled people.

The polished pathway is illustrated in the diagram on the next page.

Recommendations

- The NDIA work to significantly reduce the complexity of using NDIS supports for people with an intellectual disability and their families.
- Independent, evidence-based information is available to people with an intellectual disability and their families about NDIS planning, supports and services.
- The NDIA review and recognise barriers that people with an intellectual disability experience when looking for an included life in the community.

