Inclusion Australia

Access and Planning for people living with intellectual disability

Background Paper – NDIS Review Engagement Project

August 2023

This paper was prepared by JFA Purple Orange to support Inclusion Australia's engagement with people living with intellectual disability, their families and allies, and other stakeholders as part of consultations to inform the NDIS Review.

Introduction

The establishment of Australia's National Disability Insurance Scheme (NDIS) has produced beneficial outcomes for many people living with disability. However, there continues to be numerous shortcomings in how the Scheme operates that need to be addressed to increase its effectiveness in advancing the life chances of participants. Among them is how people living with disability access the Scheme and undertake planning. In its interim report ['What we have heard'](#), the NDIS Review describes accessing the Scheme as neither 'simple' nor 'straightforward' and recognises that planning processes are 'complex, confusing, and stressful'.[1] This resonates strongly with people living with intellectual disability and their families and allies who have found these processes particularly difficult during the first 10 years of the Scheme's operation. The current Review presents an opportunity for intellectual disability communities to help shape changes to ensure the NDIS delivers on its original promise for every participant.

Just under 100,000 NDIS participants live with intellectual disability, accounting for about 17 per cent of the total number of people with individual plans.[2] Although some feel they have gained greater independence through the Scheme, concerns have been raised that people living with intellectual disability are experiencing poorer outcomes under the NDIS than other groups.[3]

Participants with more social capital and stronger advocacy skills – or with access to this through family or other informal supports – also seem to fare much better in access and planning processes.[4]

The level of inconsistency and inequity between participant experiences may, in part, be tied to who had a seat at the table during early discussions about the new Scheme. It has been suggested the Scheme was primarily designed to meet the needs of people living with physical disability and that the views of this group dominated the early consultation processes while those of people living with intellectual disability were 'largely absent'.[5] Nevertheless, approaches adopted during implementation have also played a significant role in determining how the Scheme operates today.

Data from the National Disability Insurance Agency's (NDIA) latest [Quarterly Report](#) sheds some quantitative light on access and planning for people living with intellectual disability. Applicants living with intellectual disability are more likely to be found eligible for an individual NDIS plan than others – 95 per cent compared to 85 per cent of applicants overall.[6] Plan utilisation is impacted by many variables although, anecdotally, there has been concern that some participants living with intellectual disability use less of their plans due to not being supported to engage with planning or to understand and implement the resulting plan. However, the quantitative data paints a more nuanced picture of this. In the 12 months to 31 March 2023, participants living with intellectual disability underspent their plans by an average of almost $20,000, or about 17 per cent.[7] For comparison, the overall average underutilisation for all participants in the Scheme was about 20 per cent,[8] indicating underutilisation is a slightly less statistically significant issue on average for participants living with intellectual disability.

More notably, there is a much greater difference in plan utilisation statistics between participants living with intellectual disability with funding for Supported Independent Living (SIL) supports and those without. The former group underutilised their plans by about eight per cent while the latter group did so by about 23 per cent,[9] which is more on average than participants generally. This may suggest the anecdotal reports have some validity except where SIL providers are billing for services

from plans, but further examination of the underlying causes is required before drawing a definitive conclusion.

Outline of the paper

In this background paper, we examine access and planning processes in the NDIS for people living with intellectual disability. First, we set out a range of issues with the current approaches that people living with intellectual disability have told us about. In the second section, we provide a summary of some of the research that has been undertaken on this topic to further inform discussions about the problems that need to be addressed. Third, we identify some potential solutions that are worthy of consideration in the context of the current NDIS Review. We address access and planning processes together because many elements of the discussion are relevant to both.

Lived experience voices

JFA Purple Orange has a long track record of active engagement with people living with intellectual disability in South Australia including through hosting the Our Voice SA peer network. This paper draws on the valuable input gained when a member of the drafting team attended an Our Voice SA board meeting in late July 2023 to specifically discuss the content of this paper. It is also informed by the wide range of experiences and insights that people living with intellectual disability have shared with both JFA Purple Orange and Our Voice SA over many years. These contributions feature throughout this paper, but we have not cited each instance individually to avoid an abundance of endnotes that would reduce the accessibility of the content.

'Closed' systems

Many people living with intellectual disability continue to reside in 'closed' institutional systems, including some people who were present at the Our Voice SA board meeting. Although experiences vary, these participants have generally had less involvement in NDIS access and planning processes because existing supports were rolled into the NDIS or services have been continued under 'in kind' arrangements through state and territory governments. When transitioning to a more individualised NDIS Plan, participants in 'closed' systems may be sidelined and disempowered, with staff – often not chosen by the participant – or a family member taking the lead in interactions with the NDIA.

Although the experiences of the NDIS among participants in all disability groups vary, it is essential to highlight the significant differences that exist between the experiences of people living with disability in 'closed' systems and others. Deinstitutionalisation still has a long way to go in Australia and, even then, many people continue to navigate the deep legacy impacts of life in these systems long after transitioning into alternative community living arrangements. NDIS processes should account for these differences and ensure all aspects of the Scheme work effectively for all.

What we hear

There are a range of issues in the approach to access and planning under the NDIS. Below, we identify some of the issues people living with intellectual disability have told us about.

Limited choice and control

The NDIS has delivered greater choice and control for most people living with disability compared to pre-NDIS disability support systems that were characterised by block payments.

But people living with intellectual disability are afforded less choice and control compared to other participants.[10] A parent, sibling, other informal supporter, or paid worker – sometimes not of the participant's choosing – is more likely to take charge of access and planning processes while Local Area Coordinators (LACs) and NDIA planners may conduct planning processes in ways that avoid directly engaging with these participants. Planning processes have not been designed to be accessible for diverse needs, with very limited use of Easy Read materials, while workload pressures on staff add to a sense that meetings are often rushed without allowing time for genuine engagement with participants or for the use of supported decision making approaches.

In some instances, the participant is not even in the room during planning conversations, while, in others, they may be present but referred to in the third person making their involvement little more than tokenistic. People living with intellectual disability have told us they are not listened to and feel unheard in meetings. This absence of genuine direct engagement is more likely to result in plans that require revision or that are not implemented in ways that create positive outcomes. It also raises questions about the level of reasonable expectation for informal supporters, including, for example, ageing parents, siblings with child caring responsibilities, or those with ill-health, to undertake a heavy workload managing NDIS processes for their loved one.[11]

The roll out of the NDIS has also coincided with an increase in formal substitute decision making through guardianship arrangements. It appears the demands of NDIS planning processes and the administrative burdens of plan utilisation, such as complex provider service agreements, are driving this, with anecdotal evidence of some providers only offering supports and services if a guardianship arrangement is in place. The quantitative data indicates the extent of this increase. For example, in 2014-15, the Victorian Office of the Public Advocate (OPA) dealt with 791 new guardianship matters; by 2021-22 that number had grown to 972.[12] In the five years to 2021-22, there was a 216 per cent increase in its rate of guardianship actions and documents, rising to 281,202.[13] Significantly, the largest cohort of people under guardianship has shifted from people with dementia to now being people living with intellectual disability.[14] Likewise, the same trend is clear in South Australia, where there were 275 new matters in 2014-15, rising to 467 in 2021-22, and where people living with intellectual disability have also replaced those with dementia as the group subject to the highest rates of guardianship.[15]

The connection between the advent of the NDIS and an increase in guardianship arrangements is concerning for, among other reasons, its consequences on decision making. In 2019, the Victorian OPA stated, 'OPA considers that, in most cases, a person with cognitive impairment should not need a guardian to access or interact with the NDIS, and that the NDIA has a responsibility to assist people to become participants.'[16] Further, in 2022 the Victorian OPA concluded 'the advent of choice and control has not been accompanied by sufficient adjustments or support for decision-making, resulting in an over-reliance on the guardianship system.'[17] In South Australia, the OPA also points to guardianship for the purpose of making decisions about NDIS supports as a key driver of the increase, although also notes stricter authorisation requirements for the use of restrictive practices on participants as another contributing factor.[18]

A standout example of the consequences of limited choice and control in NDIS planning processes is found in the inadequate housing outcomes for many participants living with intellectual disability. In fact, the Victorian OPA points to delays in securing appropriate housing as a reason why people remain under guardianship arrangements for longer than they would otherwise.[19] The number of participants living in 'group houses'[20] and quasi-institutional facilities has increased in Victoria under the NDIS, with the OPA holding concerns about the challenge of how it protects participants from 'financial exploitation' by these providers.[21] The Disability Royal Commission focused its hearing on

the experiences of living in 'group houses' on Victoria where about 5,000 people were accommodated in these dwellings in 2018-19.[22] Of these, 86 per cent were people with a primary disability type of intellectual disability. In its [Public Hearing Report](), the Disability Royal Commission stated, 'it is clear that the advent of group homes has not eliminated institutional forms of violence, abuse, neglect and exploitation experienced by people with disability, particularly those with serious intellectual disabilities.'[23]

People living with intellectual disability have also shared with us their frustrations about not having a choice within the planning process about their accommodation arrangements. Often housing goals are not discussed directly with the participant so existing arrangements – no matter how ill-suited – continue indefinitely. One participant told us, 'I don't like who I live with, [but I] don't get a choice'. Further, people residing in 'closed' systems do not get a choice about who supports them, including in NDIS planning processes, representing a conflict of interest. The Disability Royal Commission has reflected on this issue further:

> *… far too many people are denied autonomy. People lack choice about the accommodation allocated to them. They often cannot choose their coresidents or those who care for them. Perpetrators of violence or abuse, whether service providers or co-residents are allowed to continue in the same accommodation as the victims … group homes sometimes employ practices insufficiently different to those used by large institutions for people with severe disabilities in an earlier era. We have heard evidence of wide spread practices that prevent the needs and preferences of individual residents in group homes being respected, leading to a diminished quality of life and, too often, to neglect and abuse. Group homes, we have also been told, often employ practices that are staff-centred and not resident-centred, with predictable consequences.[24]*

Inaccessibility

People living with intellectual disability, and indeed many others, have told us the current processes for access and planning in the NDIS are overwhelming and stressful. One person described how joining the NDIS 'felt scary'. Another indicated they did not know how to read or understand their plan, how to use it, or what it can be used for. The NDIA provides little support to ensure plans are accessible to participants, with no provisions for plans to be available in an Easy Read format. Instead, it largely relies on informal or formal supporters to fill this void, despite having no way of knowing whether this support will be provided to a participant effectively. Anecdotal evidence suggests the provision of support to fully understand a plan is patchy at best.

Information about access and planning is often inaccessible and many people do not know how to access alternative versions of documents, such as Easy Read, if and when these are available. Forms and other paperwork are long and overly complex, asking participants 'too many questions', as one person described. These problems are exacerbated by issues of digital inequality, with the NDIA being very reliant on online platforms that not everyone has access to or the digital literacy to use. When attending NDIA or Services Australia offices, participants have told us about being directed to use the computers available to the public to complete tasks themselves rather than interacting with staff who could provide face-to-face services. Attempting to contact the NDIA by phone can result in being 'given the run around' and never being able to speak to the same person for follow up. Many participants feel they have to use 'NDIS speak', which one informal supporter described as 'very middle-class language', to achieve what they need.

Repeated retelling of information

Many participants living with intellectual disability have experienced needing to tell their story over and over to different staff members at the NDIA. When following up on matters or undertaking a plan reassessment, many participants get a different person each time. One person described that it is 'sometimes very distressing to explain all over again' what they need and why. Others agreed people who do not know you are more likely to make mistakes.

Unreliable information and constant change

During the first 10 years of the NDIS there has been frequent changes to processes, rules, and interpretations of how the Scheme should operate. Participants living with intellectual disability have described being extremely confused about the rules and being told conflicting information by different people. Additionally, there is inconsistent decision-making among LACs and NDIA planners resulting in planning outcomes that are often dependent on which LAC or planner a person gets on a given day rather than on clear rules and parameters for funding. Inconsistent decisions and unreliable information are a particular issue for participants in regional, rural, and remote areas with a lot of NDIS information oriented toward people in metropolitan areas with ready access to supports and providers. Distances to travel to offices to enable face-to-face interactions present an additional barrier to Scheme access and utilisation for these people.

Deficits approach

Many people living with intellectual disability and their families find the deficits approach to accessing and planning under the NDIS distressing. Although the NDIS was not intended to focus on deficits, the current processes for access and planning mean this is what has emerged in practice. People feel they must emphasise negative things about themselves or their loved ones and find this 'depressing'. It also creates an opening whereby one person stated they were aware of others who would 'stretch the truth to get what they want', resulting in inconsistencies and unevenness in planning outcomes while also undermining trust in the Scheme. The focus on deficits in a Scheme that is intended to advance people living with disability's life chances and enable them to live good ordinary lives continues to be a vexed problem in NDIS access and planning, and for the Scheme more broadly.

What the research says

There appears to be a broad consensus that current NDIS access and planning processes are not working well for Australians living with intellectual disability and, consequently, the Scheme has had less impactful outcomes for these participants compared to other groups. In their study of planning from the perspective of adults living with intellectual disability in Perth, Elyse Perry and colleagues found:

> *a significant gap between the desired outcomes of planning support and services and the experiences of people with intellectual disability. Adults with intellectual disability … wanted their plans to address long-term life goals. Despite being recipients of individualised planning, participants discussed experiences of restricted choice and control. Planners need to support decision-making and communication needs to*

ensure adults with intellectual disability exercise choice and control to their full capacity.[25]

A review of recent research identifies many of the same issues mentioned in the previous section. Jaquie Mills and Laura Jones met participants living with profound intellectual disability involved in the Merger of Minds group and summarised their findings in 10 key themes.[26] First, the need for genuine person-centred planning, which they summed up in the statement: 'Don't plan for the NDIS – plan for the person'. Second, the benefits of modelling the way most people plan through 'natural and random ways' rather than imposing bureaucratic processes. Third, the importance of following through to demonstrate the relationship between 'expressing a desire for something and that thing actually happening' to counteract past negative experiences and build trust and safety for a person in making their views known. Fourth, adopting strategies to overcome low expectations through broadening the range of choices a person can imagine for themselves.

The fifth theme, together with themes seven to 10, relates to supported decision-making and the utilisation of alternative communication tools, including that these are made suitable for planning purposes by, for example, adding relevant vocabulary. The sixth theme is to ensure people are always supported to actively participate in the ordinary tasks of daily life to provide better foundations for understanding the Scheme because, for example, those who have never handled money or made a purchase will find it much harder to grasp the concept of funding and budgets that can be spent on particular types of supports.

Morrie O'Connor reinforces the impacts of past negative experiences for people living with intellectual disability on how they may interact with NDIS planning processes.[27] Experiences of not being listened to and others' low expectations often deter people from expressing their needs and aspirations during planning meetings. Research has also highlighted the importance of establishing access and planning pathways that support, and do not undermine, participants' emotional wellbeing.[28] Participants should be heard and treated with dignity and respect. Processes should be meaningful and result in plans that genuinely reflect participants' goals. Staff involved in access and planning should listen and reflect, be well-trained and knowledgeable about the Scheme, and present themselves with warmth and openness.

Although not at the scale of the NDIS, a number of international jurisdictions have also adopted approaches using direct payments and individual plans, including in the United Kingdom, Canada, the United States, and the Netherlands.[29] Inconsistencies and unevenness in outcomes have also been observed among participants in these jurisdictions. The importance of person-centred planning and the involvement of supporters, such as independent support brokers, personal assistants, and microboards[30], standing alongside people have been noted. In their systematic review of individualised funding approaches, Padraic Fleming and colleagues linked success to the 'importance of strong, trusting, and collaborative relationships' with paid and unpaid people who form the person's 'network of support'. Barriers to success included a 'lack of trusting working-relationships due to previous negative experiences', 'overly complex, rigid, and bureaucratic' processes, a 'general lack of clarity', inconsistency in approaches, unmet information needs, and finding and retaining suitable staff.[31]

What are the solutions?

There are a wide range of potential solutions that are worthy of consideration and further discussion in the context of the current NDIS Review. Below, we set out some that have been raised with us to stimulate discussion, although this shortlist is not intended to limit the possibilities for ideas that could improve how people living with intellectual disability access and plan under the NDIS.

Adherence to NDIS core values

One key foundational solution is to revisit the core values the NDIS was intended to promote. In its landmark 2011 report on disability care and support in Australia, the Productivity Commission proposed what it called an 'individual choice model' that would ensure people living with disability were given greater choice and control over what and how support services were delivered.[32] Yet, as mentioned above, this has not happened for people living with intellectual disability to the same extent as others. The NDIA needs to take proactive steps to ensure the way it conducts access and planning empowers all participants to realise choice and control and to reverse the increase in formal substituted decision making through guardianship.

Access and planning processes should be person-centred and designed to enable and promote supported decision-making approaches for all participants. It is reasonable to expect this will require more time for meetings and, for many participants, more than just one meeting, which is the standard practice currently. Alternative ways and means of communicating should be embraced, including through the use of new assistive technologies. NDIA staff should receive the necessary training and professional development to implement these approaches effectively and be given reasonable flexibility within processes to adapt to the needs of each participant with the goal of maximising individual choice and control.

Build simplicity into the participant pathway

The Productivity Commission was also clear that it was proposing a 'simpler approach' to disability support compared to the previous systems operated by state and territory governments.[33] Yet, in the design and implementation of NDIS processes and procedures simplicity has given way to overwhelming complexity. A second foundational solution would be to anchor all aspects of the Scheme on the principle of simplicity and ensure steps in the participant pathway are clearly defined, free of conflicts of interest, and designed to maximise impactful supports and 'transformational' outcomes.[34]

NDIA service improvements

Many people living with intellectual disability have raised with us the need for service improvements at the NDIA, particularly since the Covid-19 pandemic resulted in less face-to-face interactions. Although the advent of online meetings has suited some participants well, others want to be given the choice to return to in-person meetings. Participants living with intellectual disability also identify they would benefit from the ability to communicate with a single person at the NDIA rather than speaking to someone different each time. While we understand some improvements have been made to internal practices recently, the rate of staff turnover at the NDIA continues to present challenges to achieving this outcome. Addressing the causes of staff turnover would have benefits for both the Agency and participants.

Accessible information

Over its first 10 years, the NDIS has resulted in an over-abundance of legislative and operational documents that are extremely difficult to navigate and understand for everyone who interacts with the Scheme. There is currently a complex array of sources of information, from the legislation and rules, to strategies, frameworks, policies, guidelines, practice guides, procedures, and similar documents. The Commonwealth Auditor-General found that in April 2020 the NDIA had 30 standard operating procedures and 33 practice guides related to planning alone (plus more for Early Childhood planning),[35] reflecting the enormous proliferation of complexity. There is an urgent need to reduce document types, streamline content and requirements, and make sure all the information about a topic is available in one clear document for everyone with an interest in the Scheme. This would not only make navigating the Scheme easier but increase the transparency about how the NDIA operates and makes decisions.

With fewer documents, the NDIA would be better placed to ensure that all are available in a range of accessible formats to suit the full diversity of access needs among participants, including Easy Read and audio-visual formats. Finding and navigating relevant information would also be made much easier. Given the issues of digital inequality, all documents should be available in both printed and digital formats. Likewise, participants should be able to access their plan in their chosen format.

Improved independent advocacy and navigation supports

Individual advocacy is not a funded NDIS support, yet the ability to self-advocate or the presence of informal or formal advocacy support appears to be critical to access and planning outcomes. To address the shortfall in outcomes for participants living with intellectual disability, it is essential people can access adequate advocacy support as they navigate access and planning processes. One way to achieve this would be to return the role of LACs to their traditional articulation as an agent of the applicant or participant, rather than serving the NDIA by undertaking Agency-orientated planning functions, and by allowing people to choose their LAC.[36] Similarly, many people living with intellectual disability rely on support coordinators and plan managers in implementing and reassessing their plans, but conflicts of interest are currently common. A clearer articulation of these roles would also assist in ensuring those supporting participants are genuinely working in their interests.[37]

Importance of peer support

For people living with intellectual disability, connections with peers provide a platform for mutual information sharing, learning, social support, and emotional wellbeing. Board members of the Our Voice SA peer network stated their capacity to navigate NDIS access and planning processes and to make their own decisions have been enhanced through their involvement with the group. As noted above, there have been concerns the voices of people living with intellectual disability have taken a backseat in the development and rollout of the NDIS despite being among the larger cohorts of those accessing the Scheme. Strong representative organisations and peer support groups can help ensure these voices are heard. Sustained funding for peer networks and programs through the Information, Linkages, and Capacity Building (ILC) program, which emerged to serve what the Productivity Commission referred to as Tier 2, is essential for maintaining these benefits.

Conclusion

Many of the problems with access and planning identified in this background paper are not unique to participants living with intellectual disability. Similarly, the solutions canvassed throughout could be expected to have widespread benefits for many participants. Nevertheless, given NDIS outcomes to date for people living with intellectual disability have fallen short of those for other groups, proactive targeted action is needed to address this discrepancy. This paper is intended to support further consideration and discussion about how this can be best achieved to ensure access and planning processes are improved and people living with intellectual disability have the same beneficial outcomes from the NDIS as others.

Acknowledgements

JFA Purple Orange acknowledges and appreciates the valuable insights that board members of Our Voice SA and other people living with intellectual disability contributed to the development of this paper. We thank Inclusion Australia for the opportunity to be involved in this important engagement project in support of the NDIS Review.

About Inclusion Australia

Inclusion Australia is the national peak body for intellectual disability. We are the trusted and authentic national voice for people with an intellectual disability and their families. Previously called the National Council on Intellectual Disability (NCID) we have been advocating for the rights of people with an intellectual disability since our formation in 1954. We provide expertise and advice to Federal Government and other organisations to drive systemic change in Australia.

About JFA Purple Orange

JFA Purple Orange is an independent social profit organisation based in South Australia that undertakes systemic policy analysis and advocacy across a range of issues affecting people living with disability and their families. We also host a range of peer networks for people living with disability including people living with intellectual disability, physical and sensory disability, younger people, people from culturally and linguistically diverse backgrounds, and people in regional South Australia. Our work is characterised by co-design and informed by a model called *Citizenhood*.

Contact

Tracey Wallace
Strategy Leader
JFA Purple Orange
Email: traceyw@purpleorange.org.au
Phone: (08) 8373 8326

Maeve Kennedy
Senior Manager, Policy and Projects
Inclusion Australia
Email: maeve.kennedy@inclusionaustralia.org.au
Phone: 0448 623 834

Notes and further reading

[1] NDIS Review, 'What we have heard: Moving from defining problems to designing solutions to build a better NDIS', June 2023, p.6, available at https://www.ndisreview.gov.au/resources/reports/what-we-have-heard-report.

[2] National Disability Insurance Agency, 'NDIS Quarterly Report to disability ministers: Q3 2022-23', March 2023, p.158, Table E.10, available at https://www.ndis.gov.au/about-us/publications/quarterly-reports. Note, since the first quarter of 2017-18, the disability groups of developmental delay and global developmental delay have been countered separately from intellectual disability. However, Down syndrome is included with intellectual disability and this primary disability type accounts for about 11,000 participants.

[3] See, for example, Kostas Mavromaras, Megan Moskos, Stéphane Mahuteau, Linda Isherwood, et al., 'Evaluation of the NDIS: Final Report', February 2018, National Institute of Labour Studies at Flinders University, available at https://www.dss.gov.au/sites/default/files/documents/04_2018/ndis_evaluation_consolidated_report_april_2018.pdf.

[4] Christine Bigby, '"The Scheme was designed with a very different idea in mind of who a disabled person is": The National Disability Insurance Scheme and people with intellectual disability,' in Mhairi Cowden and Claire McCullagh (eds), The National Disability Insurance Scheme: An Australian public policy experiment, 2021, Palgrave Macmillan, Singapore, pp.257-283.

[5] Ibid, p.262.

[6] National Disability Insurance Agency, 'NDIS Quarterly Report to disability ministers: Q3 2022-23', March 2023, p.156, Table E.4, available at https://www.ndis.gov.au/about-us/publications/quarterly-reports.

[7] Ibid, p.187, Figure E.9.

[8] Ibid, p.187, Figure E.9.

[9] Ibid, pp.187-188, Figures E.10 and E.11.

[10] See further Jan Lloyd, Karen Moni, Monica Cuskelly, and Anne Jobling, 'Engaging with National Disability Insurance Scheme Planning: Perspectives of parents of an adult with intellectual disability', Journal of Intellectual & Developmental Disability, 2020, 45(3), pp.254–263, available at https://doi.org/10.3109/13668250.2019.1654275; Elyse Perry, Rebecca Waters, and Angus Buchanan, 'Experiences of National Disability Insurance Scheme planning from the perspective of adults with intellectual disability', The Australian Journal of Social Issues, 54(3), pp.210-223, available at https://onlinelibrary.wiley.com/doi/abs/10.1002/ajs4.72; and Morrie O'Connor, 'The National Disability Insurance Scheme and People with Mild Intellectual Disability: Potential Pitfalls for Consideration', Research and Practice in Intellectual and Developmental Disabilities,

2014, 1(1), pp.17-23, available at https://www.tandfonline.com/doi/abs/10.1080/23297018. 2014.908815.

[11] For further exploration of the administrative burden, see Gemma Carey, Eleanor Malbon, and James Blackwell, 'Administering inequality? The National Disability Insurance Scheme and administrative burdens on individuals', Australian Journal of Public Administration, 2021, 80(4), pp.854-872, available at https://doi.org/10.1111/1467-8500.12508; Sarah Veli-Gold et al., 'The experiences of people with disability and their families/carers navigating the NDIS planning process in regional, rural and remote regions of Australia: Scoping review', Australian Journal of Rural Health, 2023, 31(4), pp.631-647, available at https://doi.org/10.1111/ajr.13011; Sophie Yates et al., ''Faceless monster, secret society': Women's experiences navigating the administrative burden of Australia's National Disability Insurance Scheme', Health & Social Care in the Community, 2021, (30)5, pp.e2308-e2317, available at https://doi.org/10.1111/hsc.13669.

[12] Victorian Office of the Public Advocate, 'Annual Report 2018-19', p.14. available at https://www.publicadvocate.vic.gov.au/opa-s-work/our-organisation/annual-reports/opaannual-reports/219-opa-annual-report-2018-2019; and Victorian Office of the Public Advocate, 'Annual Report 2021-22', p.14, available at https://www.publicadvocate.vic.gov.au/opa-swork/our-organisation/annual-reports/opa-annual-reports/550-opa-annual-report-2021-2022.

[13] Victorian Office of the Public Advocate, 'Annual Report 2021-22', p.14. available at https://www.publicadvocate.vic.gov.au/opa-s-work/our-organisation/annual-reports/opaannual-reports/550-opa-annual-report-2021-2022.

[14] Ibid, p.5.

[15] South Australian Office of the Public Advocate, 'Annual Report: 2014-15', pp.51&54, available at https://www.opa.sa.gov.au/documents/annual-reports/OPA-annual-report-2014-15.pdf; and South Australian Office of the Public Advocate, 'Annual Report: 2021-22', pp.13&15, available at https://www.opa.sa.gov.au/documents/annual-reports/OPA-Annual-Report-2021-22.pdf.

[16] Victorian Office of the Public Advocate, 'Annual Report 2018-19', p.34, available at https://www.publicadvocate.vic.gov.au/opa-s-work/our-organisation/annual-reports/opaannual-reports/219-opa-annual-report-2018-2019.

[17] Victorian Office of the Public Advocate, 'Annual Report 2021-22', p.5, available at https://www.publicadvocate.vic.gov.au/opa-s-work/our-organisation/annual-reports/opaannual-reports/550-opa-annual-report-2021-2022.

[18] South Australian Office of the Public Advocate, 'Annual Report: 2021-22', p.1, available at https://www.opa.sa.gov.au/documents/annual-reports/OPA-Annual-Report-2021-22.pdf.

[19] Victorian Office of the Public Advocate, 'Annual Report 2021-22', p.5, available at

https://www.publicadvocate.vic.gov.au/opa-s-work/our-organisation/annual-reports/opaannual-reports/550-opa-annual-report-2021-2022.

[20] We deliberately use the term 'group houses' rather than the more common 'group homes' because the use of 'home' in this context is a misnomer, and the use of the word 'home' in the phrase 'group home' profoundly compromises its true meaning. 'Group houses' have the character of facilities, not homes, where staff are front and centre and people living with disability are congregated, disempowered, and segregated from their communities. Moreover, living in such a facility does not fulfill the promise of the NDIS to enable all Australians to enjoy good ordinary lives.

[21] Victorian Office of the Public Advocate, 'Annual Report 2021-22', p.5, available at https://www.publicadvocate.vic.gov.au/opa-s-work/our-organisation/annual-reports/opaannual-reports/550-opa-annual-report-2021-2022.

[22] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 'Public Hearing Report: Public hearing 3 - The experience of living in a group home for people with disability', 2019, p.11. available at https://disability.royalcommission.gov.au/publications/report-public-hearing-3-experience-living-group-home-people-disability.

[23] Ibid, p.82.

[24] Ibid.

[25] Elyse Perry, Rebecca Waters, and Angus Buchanan, 'Experiences of National Disability Insurance Scheme planning from the perspective of adults with intellectual disability', The Australian Journal of Social Issues, 54(3), p.220, available at https://onlinelibrary.wiley.com/doi/abs/10.1002/ajs4.72.

[26] Jaquie Mills and Laura Jones, 'Increasing AACcess to information, choice and control for NDIS planning: A project in co-design', Intellectual Disability Australasia, 2018, 39(3), pp.16-19, available at https://search.informit.org/doi/10.3316/INFORMIT.973584138782009.

[27] Morrie O'Connor, 'The National Disability Insurance Scheme and People with Mild Intellectual Disability: Potential Pitfalls for Consideration', Research and Practice in Intellectual and Developmental Disabilities, 2014, 1(1), pp.17-23, available at https://www.tandfonline.com/doi/abs/10.1080/23297018.2014.908815.

[28] See further in Kostas Mavromaras, Megan Moskos, Stéphane Mahuteau, Linda Isherwood, et al., 'Evaluation of the NDIS: Final Report', February 2018, National Institute of Labour Studies at Flinders University, available at https://www.dss.gov.au/sites/default/files/documents/04_2018/ndis_evaluation_consolidated_report_april_2018.pdf; Jaquie Mills and Laura Jones, 'Increasing AACcess to information, choice and control for NDIS planning: A project in codesign', Intellectual Disability Australasia, 2018, 39(3), pp.16–19, available at https://search.informit.org/doi/10.3316/INFORMIT.973584138782009; Elyse Perry, Rebecca

Waters, and Angus Buchanan, 'Experiences of National Disability Insurance Scheme planning from the perspective of adults with intellectual disability', The Australian Journal of Social Issues, 54(3), p.220, available at https://onlinelibrary.wiley.com/doi/abs/10.1002/ajs4.72.

[29] See further, Pádraic Fleming et al., 'Individualized funding interventions to improve health and social care outcomes for people with a disability: A mixed-methods systematic review', Campbell Systematic Reviews, 2019, available at https://www.campbellcollaboration.org/betterevidence/personal-budgeting-outcomes-people-with-disability.html; Vanessa Davey et al.,
'Direct Payments: A National Survey of Direct Payments Policy and Practice', May 2007, Personal Social Services Research Unit, London School of Economics and Political Science, available at https://www.pssru.ac.uk/pub/dprla.pdf; Sheila Riddell et al., 'Disabled People and Direct Payments: A UK Comparative Study', August 2006, available at http://www.docs.hss.ed.ac.uk/education/creid/Projects/10i_Directpyts_FinalRpt_I.pdf; Robbi Williams, 'Individualised Funding: General Considerations On Implementation', 2008, Julia Farr Association, Adelaide Australia, available at https://www.purpleorange.org.au/application/files/3315/4223/7244/RESEARCH_SELF-DIRECTED_SUPPORT_Purple_Orange_-__Individualised_Funding_general_considerations_on_implementation.pdf; Simon Duffy and Robbi Williams, 'The Road to NDIS: Lessons from England about Assessment and Planning', October 2012, Julia Farr Association, available at https://www.purpleorange.org.au/what-we-do/library-our-work/road-ndis-lessonsengland-about-assessment-and-planning.

[30] For more information about microboards, visit https://microboards.org.au/microboardscommunity/what-is-a-microboard/.

[31] Pádraic Fleming et al., 'Individualized funding interventions to improve health and social care outcomes for people with a disability: A mixed-methods systematic review', Campbell Systematic Reviews, 2019, pp.4-5, available at https://www.campbellcollaboration.org/betterevidence/personal-budgeting-outcomes-people-with-disability.html.

[32] Productivity Commission, 'Disability Care and Support,' Report no.54, 2022, Canberra, p.30, available at https://www.pc.gov.au/inquiries/completed/disability-support/report.

[33] Ibid, p.440.

[34] We have written about a simple participant pathway and the differences between 'transactional' and 'transformation' impacts as part of our NDIS Review Conversation Series. To access these papers, visit https://www.purpleorange.org.au/news-resources/ndis-conversationseries.

[35] Auditor-General, 'Decision-making Controls for NDIS Participant Plans: National Disability Insurance Agency', Auditor-General Report No.14 2020-21 – Performance Audit, Australian National Audit Office, p.24, available at https://www.anao.gov.au/sites/default/files/AuditorGeneral_Report_2020-21_14.pdf.

[36] We have written more about the role of LACs in our NDIS Review Conversation Series. To access this paper, visit https://www.purpleorange.org.au/news-resources/ndis-conversationseries/ndis-paper-2.

[37] We have written more about intermediary roles in our NDIS Review Conversation Series. To access this paper, visit https://purpleorange.org.au/news-resources/ndis-conversation-series/ndis-review-paper-11.