Safeguarding the rights and interests of people with disability



Joint Standing Committee on the National Disability Insurance Scheme

Inquiry into the capability and culture of the NDIA

October 2022

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Contents

Abb	bbreviations	
Red	ecommendations	4
1.	Introduction	8
	1.1 About the Office of the Public Advocate	
	1.2 OPA's engagement with Committee inquiries	9
	1.3 A human rights approach	9
	1.4 About this submission	
2.	Supported decision-making	9
3.	Access to the NDIS and cultural safety for Aboriginal and Torres Strait Islander pa	articipants. 11
4.	Workforce capability	12
	4.1 The NDIA	12
	4.2 The NDIS national workforce	13
5.	Market stewardship	14
	5.1 Service providers	14
	5.2 Specialist Disability Accommodation	15
6.	Safeguarding	18
7.	Lack of transparency and focus on financial sustainability	20
8.	Expert Assessment vs 'value for money'	22

Abbreviations

APTOS Applied Principles and Tables of Support

CISO Corrections Independent Support Officer

ITP Independent Third Person

NDIA National Disability Insurance Scheme

OPA Office of the Public Advocate

PLP Pension-Level Projects

RACF Residential Aged Care Facility

SAVVI Supporting Accommodation for Vulnerable Victorians Initiative

SDA Specialist Disability Accommodation

SIL Supported Independent Living

SRS Supported Residential Services

STA Short Term Accommodation

UNCRPD United Nations Convention on the Rights of Persons with Disabilities

Recommendations

Recommendation 1

The National Disability Insurance Agency should provide decision support for participants who require it to promote the human rights of people with disability to exercise choice and control.

Recommendation 2

The National Disability Insurance Agency should fund:

- Decision support for day-to-day lifestyle, personal and financial decisions
- Decision support in advance of significant life transitions
- Decision support for NDIS-related planning.

Recommendation 3

The National Disability Insurance Agency should provide capacity building and training opportunities, supported decision-making tools and resources for non-professional decision-supporters.

Recommendation 4

The National Disability Insurance Agency should continue to fund innovative supported decision-making initiatives.

Recommendation 5

The National Disability Insurance Agency should develop guidelines that define the scope and responsibilities of the Decision-Supporter role, to include an advocacy element.

Recommendation 6

The National Disability Insurance Agency's administrative processes should be sufficiently flexible to ensure that participants can implement decisions made with support.

Recommendation 7

The National Disability Insurance Agency and Australian, state and territory governments should take a more active approach to market stewardship, ensuring that First Nations people with disability have access to services on country in their own communities.

Recommendation 8

The National Disability Insurance Agency should advance as a matter of urgency its Maintaining Critical Supports and Immediate Support Response arrangements, and other market steward arrangements, to increase culturally safe and culturally appropriate services and accommodation options for First Nations people with disability, including options appropriate for both younger people and Aboriginal Elders.

Recommendation 9

Current best-practice in supported decision making for First Nations people with disability should be developed, shared and improved through Aboriginal-controlled projects, as part of wider self-determination processes and initiatives, resourced by the National Disability Insurance Agency and Australian governments' justice departments.

Recommendation 10

The National Disability Insurance Agency should, in its review of the New Starter Program, establish a requirement that all planners and Local Area Coordinators (LAC) have relevant disability and mental health training.

Recommendation 11

The National Disability Insurance Agency should develop a national training program for planners and support coordinators.

Recommendation 12

The National Disability Insurance Agency should develop and implement a monitoring and evaluation strategy for the *NDIS National Workforce Plan 2021-25*.

Recommendation 13

The National Disability Insurance Agency should require that all behaviour support practitioners and SIL workers have a competency standard equivalent to Certificate IV in disability to ensure consistent and safe supports across the system and to help prevent potentially harmful behaviours.

Recommendation 14

The Australian Government, in collaboration with the NDIS Quality and Safeguards Commission, should amend the *National Disability Insurance Scheme (Code of Conduct) Rules 2018* and related guidance to reflect a zero-tolerance approach to abuse.

Recommendation 15

The National Disability Insurance Agency should publish, consult on and implement its Maintaining Critical Supports and Immediate Support Response policy and framework as a matter of urgency. This policy and framework should ensure that:

- multiple designated providers of last resort are clearly identified;
- providers of last resort are adequately resourced to enable them to respond immediately in situations of market failure which includes having staff available on short notice:
- the providers and their staff have specialised experience, skill and expertise that are relevant to the specific needs of participants;
- clear procedures exist to guide planners, local area coordinators and support coordinators when the need arises for a provider of last resort to provide any approved support (not just 'critical' supports);
- participant plans have built-in flexibility for situations in which a provider of last resort is required, including the ability to access contingency funding;
- as soon as possible, participants are transitioned back to support outside provider of last resort arrangements.

Recommendation 16

The National Disability Insurance Agency as market steward, in collaboration with federal, state and territory governments, should consider the effectiveness of the specialist disability accommodation (SDA) pricing framework under the National Disability Insurance Scheme.

The review should consider:

- the availability, diversity, and stability of SDA;
- mapping current SDA and identifying gaps in the market;
- whether clients most in need of SDA are prioritized;
- · ways to stimulate the SDA market;
- robust builds for situations of crises;
- provider of last resort arrangements.

Recommendation 17

The National Disability Insurance Agency, in conjunction with federal, state and territory governments, should adjust market levers and policies (including the pricing framework) to stimulate and ensure the existence of sufficient numbers and diversity of crisis accommodation providers, and should also ensure that sufficient funds are provided so that Specialist Disability Accommodation provision is able to meet existing and future demand.

Recommendation 18

The National Disability Insurance Agency's Maintaining Critical Supports and Immediate Support Response policy and framework should specifically address and provide guidance in relation to Specialist Disability Accommodation and crisis accommodation providers of last resort. The framework should include a vacancy management strategy for providers to prioritise clients with the most urgent need.

Recommendation 19

The National Disability Insurance Agency should enable contingency funding to be immediately accessible when crises arise. This approach would require designated liaison and emergency contact points and procedures within the NDIA (or authorised agencies) which are responsive during and outside of business hours.

Recommendation 20

The National Disability Insurance Agency should directly commission the provision of appropriate Short-Term Accommodation and Assistance (STAA) for participants who need accommodation at short notice.

Recommendation 21

The National Disability Insurance Agency should work with federal, state and territory governments to enact legislative and other safeguards to provide security of tenure and other rights protections for all forms of accommodation used by NDIS participants, including people in Specialist Disability Accommodation.

Recommendation 22

The National Disability Insurance Agency and the NDIS Quality and Safeguards Commission should consult with relevant stakeholders and the broader community on the scope of its Vulnerable Participants Framework and the process for working with participants who are identified as vulnerable, to ensure it offers them adequate protection from violence, abuse, and neglect in the context of NDIS service delivery.

Recommendation 23

The National Disability Insurance Agency should put in place a policy that support coordinators should ordinarily be independent of a participant's accommodation and core support providers.

Recommendation 24

Section 16 of the *NDIS Act 2013* should be amended to state that the National Disability Insurance Agency may fund any assessment that is requested or required in the preparation of a plan or as part of a plan review.

Recommendation 25

The *NDIS Act 2013* should be amended to require the National Disability Insurance Agency to provide written reasons in an accessible format, on request from a participant or person acting on their behalf, regarding discrepancies between requested and approved supports.

Introduction 1.

The Public Advocate of Victoria welcomes this opportunity to submit to the Federal Parliamentary Inquiry by the Joint Standing Committee (the Committee) on the National Disability Insurance Scheme (NDIS) on the Capability and Culture of the NDIA (the Inquiry).

1.1 **About the Office of the Public Advocate**

The Office of the Public Advocate (OPA) is a Victorian statutory office, independent of government and government services that works to safeguard the rights and interests of people with disability.

The Public Advocate is appointed by the Governor in Council and is answerable to the Victorian State Parliament. The Public Advocate has functions under the Guardianship and Administration Act 2019 (Vic), all of which relate to promoting the independence and human rights of people with disability and protecting people with disability from abuse, neglect and exploitation. To this end, OPA provides a range of critical services for people with cognitive impairment or mental illness, including guardianship, advocacy, and investigation services.

In 2020-21, OPA was involved in 1941 guardianship matters (964 of which were new), 425 investigations, and 352 cases requiring advocacy. OPA's Disability Act officers assist the Office to fulfil its advocacy and safeguarding roles in relation to tenancy rights of people living in disability residential services, and the civil detention and compulsory treatment provisions in the Disability Act 2006 (Vic). The officers' interventions remain the largest single contributor to OPA's individual advocacy.

A key function of the Public Advocate is to promote and facilitate public awareness and understanding about the Guardianship and Administration Act, and any other legislation affecting persons with disability or persons who may not have decision-making capacity. To do so, OPA maintains a full-service communications function including media outreach, and runs an Advice Service which provided 11,619 instances of advice or information during the 2020-21 financial year. OPA also coordinates a community education program for professional and community audiences across Victoria on a range of topics such as the role of OPA, guardianship and administration, and enduring powers of attorney. In 2020-21, OPA delivered 73 education sessions for an audience of 2273 people.

OPA is supported by approximately 600 volunteers across three volunteer programs: the Community Visitors Program, the Independent Third Person Program (ITP Program) and the Corrections Independent Support Officer (CISO) Program.

Community Visitors are Victorian Governor in Council appointed volunteers who play a vital role in safeguarding the rights of people with disability and fostering their inclusion in the community. They are empowered to make unannounced visits to supported accommodation facilities to monitor and report on the services and quality of care being provided to residents and patients. They are appointed under three separate Acts of Parliament. 1 In 2020-21, 337 Community Visitors made 3718 visits either in person or remotely, visiting 1467 sites.²

The ITP Program is a 24/7, state-wide volunteer service operating in all police stations in Victoria. ITPs assist persons with cognitive impairment when giving interviews and making formal statements to Victoria Police. In 2020-21, ITPs attended a total of 3631 interviews and statements. CISOs are experienced ITPs who support prisoners who have an intellectual disability at General Manager's Disciplinary Hearings at Victorian prisons and/or remand centres. In 2020-21, CISOs were invited to attend 74 hearings for 106 charges.

¹ The Disability Act 2006 (Vic), the Mental Health Act 2014 (Vic), and the Supported Residential Services (Private Proprietors) Act 2010 (Vic).

² Office of the Public Advocate, Community Visitors Annual Report (2021) 10

1.2 OPA's engagement with Committee inquiries

OPA considers that the NDIS is a major social and human rights reform that has the potential to positively transform the lives of the people with disability who qualify for it and to create more positive attitudes towards people with disability in the broader community because of their greater inclusion and participation in it. Nevertheless, OPA recognises that there is a long way to go before it can be said that the NDIS is providing the improvements to the lives of people with disability that had been envisaged. This is especially the case for people with cognitive disability and complex support needs. To that end, OPA has made several submissions to the Committee so that OPA's extensive engagement with the NDIS can be used to point to its benefits as well as to how to improve it.

OPA has made submissions to the Committee between 2019 and 2022 on such topics as Planning, Supported Independent Living, Workforce, Quality and Safeguards Commission, Independent Assessments, and the current scheme's implementation and forecasting. This submission will draw on these previous submissions and on appropriate material from other OPA submissions and reports as well as relevant observations from OPA staff and volunteers.

1.3 A human rights approach

This submission applies a human rights approach that:

- a. holds that all people with disability have the right to enjoy equality of opportunity and to effectively participate in, and be fully included in, society
- recognises that most challenges experienced by people with disability are a result of disabling systems and environments, rather than being due to an inherent 'lack' in the individual
- c. considers impairment as an expected dimension of human diversity
- d. seeks for people with disability to be supported and resourced to have the capabilities to lead a dignifying and flourishing life.

1.4 About this submission

The submission fully addresses the Inquiry's terms of reference, including:

- a. the capability and culture of the National Disability Insurance Agency (NDIA), with reference to operational processes and procedures, and nature of staff employment
- the impacts of NDIA capability and culture on the experiences of people with disability and NDIS participants trying to access information, support, and services from the Agency; and
- c. any other relevant matters.

2. Supported decision-making

Supported decision-making is the provision of support which enables a person with a cognitive disability to exercise their legal decision-making rights enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPCD) to which Australia is a signatory.

Article 12 of the UNCRPD obliges States Parties to recognise that persons with disabilities should enjoy legal capacity on an equal basis with others in all aspects of life, and to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Consistent with this commitment, over the last decade Victoria has reformed a number of laws, including the Guardianship and Administration Act 2019, the Medical Treatment Planning and Decisions Act 2016, the Powers of Attorney Act 2014, and the Mental Health Act 2014, to enable people to appoint a person (or people) they trust to support them with a variety of legal decisions. The appointed person is called a decision-supporter.

While the NDIA has commenced work on the co-design of a Supported Decision Making policy and implementation plan, there is no similar legislative provision authorising the use of a decision-supporter in the context of the NDIS. While nominees can be appointed, significant further work is required to truly realise the rights of people with disability to enjoy legal capacity on an equal basis with the broader community, both in the context of the NDIS as well as in Australian society more generally.

NDIS funding must enable the day-to-day lifestyle, personal and financial decisions of a person who requires the skilled support of a decision-supporter. This requires the provision of decision-making support, over a period of time, in order to build the decision-making capacity of participants.

Evidence of the importance of decision-making capacity building emerged during the 2016 OPA and VALID pilot supported decision-making project (the OVAL project³). Under the trial, volunteers were trained and supported to work with NDIS participants. A key learning from this project was that many of the participants had few prior opportunities to make decisions, with or without support, in their day-to-day lives. This meant that they were overwhelmed when faced with the level of decision-making required in relation to their NDIS Plan. Opportunities for the development of decision-making skills, over time and as part of day-to-day life, were observed to be a necessary element of decision-making capacity building.

High quality and skilled decision support is a requirement for the enactment of the human rights of people with disability who require support to exercise choice and control in their lives. For those who have friends or family who can act in the role of decision supporter, those friends or family should have access to high quality resources, tools, as well as capacity-building training to enable best practice. Accessible, NDIS-related, decisionmaking information must be available to all decision-supporters. For those who do not have these natural supports in the community, the NDIA must fund decision support programs to enable choice and control to allow people with disabilities to exercise their rights.

In relation to NDIS-related decisions, the role of the decision-supporter in implementing decisions may be complex. Primarily, the decision-supporter must ensure that NDIS Support Coordinators are fully aware of, and engaged with the decisions made as part of the supported decision-making process. They must also ensure that service providers deliver services in line with decisions made. The role of decision-supporter must, therefore, include a formal and recognised advocacy element in order to ensure the effective implementation of participants' decision-making. For example, the decision-supporter may support the participant to make complaints, or make complaints on their behalf, seeking outcomes in line with decisions made. Complaints may concern instances of Support Coordinators or service providers not fulfilling their obligations to implement the decisions in line with the participants' will and preferences.

The provision of decision-making support, together with accessible policies and procedures are preconditions to ensuring access to the scheme without an over-reliance on substitute decision-making. OPA has observed that an over-reliance on substitute decision-makers is particularly evident where support is needed for NDIS participants to complete administrative requirements of the NDIS access and planning process.

OPA submission Joint Standing Committee NDIS inquiry on the capability and culture of the NDIA

³ Office of the Public Advocate, Volunteer Programs of Support for Decision-Making: Lessons and recommendations from the OVAL Project (2017)

As noted in the 2021 OPA Annual Report, some 15 per cent of all new guardianship orders this year were the result of there being no other less-restrictive option to make NDIS decisions for a person with disability.⁴ A consequence of this has been a change in the demographic profile of OPA guardianship clients. The number of people with mental health issues and intellectual disability subject to guardianship has increased over the past five years. As of the 2021 OPA Annual Report, approximately a third of those subject to guardianship were people with intellectual disability (364 of 964 guardianship matters OPA was involved in) and a third were people with a diagnosis of mental illness (360 out of 964)⁵. This trend has continued since the date of that report. This administrative use of guardianship is extremely concerning, and OPA is investigating less-restrictive ways in which people with a disability may be able to interact with the scheme, for example, by the use of a statement of support rather than a formal contract.⁶

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The National Disability Insurance Agency should develop guidelines that define the scope and responsibilities of the Decision-Supporter role, to include an advocacy element.

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The National Disability Insurance Agency's administrative processes should be sufficiently flexible to ensure that participants can implement decisions made with support.

3. Access to the NDIS and cultural safety for Aboriginal and Torres Strait Islander participants

The discussion below should be caveated with the acknowledgement that OPA does not seek to represent itself as the voice of Aboriginal and Torres Strait Islander people with disability. The recommendations made in this component of the submission are based on

⁴ Office of the Public Advocate, Annual Report 2020 – 2021 (2021) 6.

⁵ Ibid 13.

⁶ ld.

previous work undertaken by OPA with Connecting Home. As shown in OPA and Connecting Home's submission to the Disability Royal Commission's Issues Paper on First Nations People with disability⁷, Aboriginal people's experiences of disability sit in the context of compounding disadvantage caused by experiences of colonisation and systemic racism.

Aboriginal people experience issues accessing universal services, including interactions with the NDIA and contracted service providers. As noted in the National Aboriginal Community Controlled Health Organisation's (NACCHO's) most recent submission to the Joint Standing Committee on the NDIS, some Aboriginal people find that access to the NDIS is based on assumptions that exclude them (for example, having access to online services, transport, or somebody who can advocate on their behalf), and the system does not always provide for needs specific to Aboriginal people, such as sorry business and interpreter services.

Those who live in regional and remote areas experience the issue of thin markets acutely, with no disability services available at all where they live, let alone Aboriginal community-controlled services. Aboriginal community-controlled health services, which provide primary healthcare services to up to half of the Aboriginal population, are also experiencing issues in the delivery of NDIS services even though they express support for the NDIS and are motivated to assist the most vulnerable members of their community. These barriers, articulated in the NACCHO submission, include thin markets resulting in the inability to provide services competitively, an insufficient workforce, and large upfront investments required to establish NDIS services being out of reach for most Aboriginal community-controlled health services.

Recommendation 7

The National Disability Insurance Agency and Australian, state and territory governments should take a more active approach to market stewardship, ensuring that First Nations people with disability have access to services on country in their own communities.

Recommendation 8

The National Disability Insurance Agency should advance as a matter of urgency its Maintaining Critical Supports and Immediate Support Response arrangements, and other market steward arrangements, to increase culturally safe and culturally appropriate services and accommodation options for First Nations people with disability, including options appropriate for both younger people and Aboriginal Elders.

Recommendation 9

Current best-practice in supported decision making for First Nations people with disability should be developed, shared and improved through Aboriginal-controlled projects, as part of wider self-determination processes and initiatives, resourced by the National Disability Insurance Agency and Australian governments' justice departments.

4. Workforce capability

4.1 The NDIA

Agency staff and planners shape the experience of NDIS participants by, among other things, supporting them to identify their goals and aspirations and determine the supports

OPA submission Joint Standing Committee NDIS inquiry on the capability and culture of the NDIA

⁷ Office of the Public Advocate and Connecting Home, Submission to the Royal Commission on Violence, Abuse, Neglect and Exploitation in Disability Care, The Experience of First Nations People with Disability in Australia Issues Paper (2021)

that will be required to fulfil these. To achieve this in a meaningful way, planners (and other delegates of the CEO) need an in depth understanding of disability.

OPA staff observe that planners have varying degrees of experience and expertise, and a range of qualifications. Some planners demonstrate an in-depth understanding of disability and can, for instance, directly estimate the required number of hours per service during a planning meeting. In contrast, other planners come to the role with a more superficial knowledge base and as a result, are less precise in their recommendations as to what should be included in a participant plan.

Recommendation 10

The National Disability Insurance Agency should, in its review of the New Starter Program, establish a requirement that all planners and Local Area Coordinators (LAC) have relevant disability and mental health training.

Recommendation 11

The National Disability Insurance Agency should develop a national training program for planners and support coordinators.

4.2 The NDIS national workforce

The NDIA also plays a crucial role in recruiting, retaining, and developing the disability services workforce. To this end, the *NDIS National Workforce Plan: 2021-25* (the Plan) was developed with four key priorities, including supporting and retaining existing workers, growing the future workforce, maintaining quality of participant supports delivered by workers, and supporting sector efficiency and innovation.⁸

The Plan acknowledges the key challenges facing the sector, including poor perception of the sector and unsupported entry pathways hindering recruitment, variable and disconnected work conditions with limited training opportunities impacting retention and quality, and red tape and difficulties in adapting service models reducing the time that workers spend supporting participants. The increasingly precarious and casualised nature of work in the disability sector and the lack of support across the employee lifecycle identified in the Plan are arguably reflective of the broader economic conditions under which disability services are provided – casualisation and precarity are increasingly being observed across a range of sectors. Nonetheless, improving working conditions for the NDIS workforce and ensuring they are supported to provide high-quality services should remain a priority, and it is pleasing that the NDIA has acknowledged this through the development of the Plan. The Plan articulates four key priorities in addressing these issues, including growing and supporting the NDIS workforce, including retaining existing workers, attracting new workers, and maintaining and improving the quality of support delivered by workers.

One flaw of the Plan is the lack of clarity around how these initiatives, and the benefits they are envisioned to bring, will be quantified and monitored over time. While the initiatives in the Plan are commendable, clear evidence will be required to support the evaluation and continued implementation of the Plan across its lifespan and beyond. It is not clear how, for example, the Plan can or will be evaluated against its stated objectives at its halfway point. This would allow the NDIA to evaluate the quality of its implementation efforts, and revise components as issues arise or a lack of effectiveness becomes apparent.

Notably, the key issue of violence, abuse and neglect identified by OPA in its report <u>I'm too scared to come out of my room</u>: Preventing and responding to violence and abuse between co-residents in group homes is absent from the *Plan*. This report demonstrated that violence and abuse is commonly experienced by group home residents, both from co-

⁸ Australian Government, NDIS National Workforce Plan: 2021-2025 (2021)

⁹ Ibid 15.

¹⁰ Ibid 5.

residents and group home staff. The report identified a lack of capability of staff to identify and respond to violence and abuse in a timely manner as a key reason for the prevalence of these experiences. This lack of capability sometimes results in disability workers expressing the view, whether explicitly or implicitly, that violence in group homes is inevitable and acceptable. Encouraging a relationship-based culture within services that prevents violence from occurring, and facilitates disclosures when it does, as well as upskilling the disability workforce around the drivers of violent or abusive behaviours and alternative support strategies for preventing them, will go some way towards reducing these experiences for group home residents.

Recommendation 12

The National Disability Insurance Agency should develop and implement a monitoring and evaluation strategy for the *NDIS National Workforce Plan 2021-25*.

Recommendation 13

The National Disability Insurance Agency should require that all behaviour support practitioners and SIL workers have a competency standard equivalent to Certificate IV in disability to ensure consistent and safe supports across the system and to help prevent potentially harmful behaviours.

Recommendation 14

The Australian Government, in collaboration with the NDIS Quality and Safeguards Commission, should amend the *National Disability Insurance Scheme (Code of Conduct) Rules 2018* and related guidance to reflect a zero-tolerance approach to abuse.

5. Market stewardship

Related to the NDIA's role in developing the capability of the disability services workforce is its role as market steward for the NDIS. The second aspiration envisioned in the *NDIA Corporate Plan 2022-26* is for a competitive market with innovative supports, with a focus on developing the market with high-quality, competitive and innovative supports and services, and improving the NDIS provider experience.¹¹

However, the current experience of individuals with a cognitive disability, or multiple and complex needs, is that the high-level supports required to participate in the community and live an ordinary life are not always available – indeed, in many cases, there is no support available at all. OPA has written extensively on the topic of thin markets in the NDIS, with a particular focus on the impacts for people with complex support needs in its <u>submission to the NDIS</u> as part of the Thin Markets Project, and in its report <u>The Illusion of Choice and Control</u>: The difficulties for people with complex and challenging support needs to obtain adequate supports under the NDIS. Drawing on examples observed by OPA Community Visitors and Advocate Guardians, the stories told throughout the report highlight an urgent need for the NDIA to direct focused and sustained efforts towards developing competitive and comprehensive markets for support to access the NDIS, and create then implement NDIS plans. The Illusion of Choice and Control identified four areas in which challenges are faced by participants: accessing the NDIS, planning supports, obtaining service providers, and retaining accommodation. This submission will discuss thin markets in the context of the last two areas.

5.1 Service providers

As highlighted by the Productivity Commission, the Joint Standing Committee and the McKinsey and Company review, thin markets are particularly acute for people with multiple

¹¹ National Disability Insurance Agency, *Corporate Plan 2022-26* (undated)

and complex needs. Though they may have substantial amounts of funding available through their NDIS plans, many service providers are unwilling to assist them because of the complexity, challenges and potential risks involved in meeting their needs. Accordingly, they decline referrals outright or withdraw services when problems arise.

The problem of thin markets can produce catastrophic outcomes for NDIS participants in the absence of provider of last resort arrangements which the NDIA and Victorian and Australian governments have not yet finalised. Prior to the NDIS, in Victoria, the former Department of Health and Human Services (DHHS) was ultimately responsible for supporting people with complex needs and could be relied on to provide supports and ensure a person did not become homeless even in challenging circumstances. In situations where political fallout was likely to arise as a consequence of withdrawing all support from an individual and leaving them no other options DHHS would act effectively as the provider of last resort. Under the NDIS, the Joint Standing Committee and others have noted evidence of private service providers cherry-picking the clients they are willing to provide services to, with no incentive to provide supports to participants with particularly complex support needs. This is a foreseeable outcome of the design of the scheme when pricing fails to take into consideration differences in the resource intensity of services required by participants. The consequence of this is that participants in the NDIS who may have more complex needs have regularly found themselves with inadequate supports, or no supports at all, for extended periods of time - leading them to adverse outcomes including homelessness and contact with the criminal justice system, as illustrated in the case studies in The Illusion of Choice and Control.

Even where a support provider has been engaged, concerns have been raised about the quality of the services and their practices in a number of cases. People who require access to complex support are often unable to find and contract with suitable service providers or to respond assertively to poor service quality in the NDIS market. On at least one occasion OPA is aware of, a person had to relocate in order to access services.

The difficulty in accessing appropriate supports has in some cases resulted in participants having contact with civil and criminal detention settings, such as secure extended care in mental health settings, or remand centres and prison. Frustratingly, the lack of qualified supports in the community often then prevents these same people from being able to exit those detention settings in a timely and safe manner, leaving them effectively trapped until adequate supports in the community become available. Issues with discharging people from hospital is also commonly observed as a result of poor or non-existent service availability in the community. OPA has consistently observed the serious and long-lasting impacts on people's mental and physical wellbeing as a result.

With respect to hospital discharge issues, it is encouraging that the Australian Government has recently committed to an increase in the number of hospital liaison officers, and has set new targets for NDIS participants being discharged from hospital. The new targets require an NDIS planner to meet with a participant within four days of them being ready for discharge, and to create an NDIS plan within 15 to 30 days. While these targets are commendable, they do not necessarily address the underlying gaps in services that have caused these delays previously. It will be difficult for planners to meet these new targets if issues such as the availability of suitably qualified occupational therapists and other key professionals is not addressed, or appropriate accommodation options are not available or cannot be funded.

5.2 Specialist Disability Accommodation

Locating suitable accommodation was the other major barrier to experiencing the transformational benefits of the NDIS for almost all people whose stories were told in *The Illusion of Choice and Control*. Stable and suitable accommodation is a necessary basis for a person to access almost all other types of services. Unfortunately, this is out of reach for many NDIS participants.

While housing and accommodation are primarily state responsibilities. OPA considers that the NDIA has a critical role to play in securing appropriate accommodation for participants whose disability means that they need to access specialised housing through the Specialist Disability Accommodation (SDA) market. SDA is housing that has been specially designed or modified to suit the needs of people who have an extreme functional impairment or very high support needs. It is estimated that around 6% (28,000) of NDIS participants will be eligible for SDA funding.¹²

OPA and Community Visitors have expressed concerns about the scarcity of SDA for NDIS participants who need high levels of highly skilled support. In Victoria, as of 31 March 2021, there were only a total of 85 SDA providers who had ever been active, with 53 of them active during guarter 3 of FY 2020-21¹³ As of 30 June 2022, there were 142,240 people participating in the NDIS in Victoria. 14 If approximately 6% of NDIS participants are expected to access SDA, this would total 8,534 Victorian NDIS participants who were eligible for SDA. Based on these workings alone, there is clearly a significant shortfall in the availability of SDA for Victorian NDIS participants.

Further, OPA is concerned that despite evidence that congregate living arrangements lead to poorer outcomes for people with disability, the NDIS and the introduction of SDA funding is not leading to much needed change in this area. To this point, the United Nations report on Australia's Review of the UNCRPD raised concerns that the SDA framework 'facilitates and encourages the establishment of residential institutions and will result in persons with disabilities having to live in particular living arrangements to access NDIS supports.'15 The continued reliance on the congregate care model of SDA appears to be premised on the prioritisation of short-term financial sustainability above all other policy considerations, including respect for the human rights of NDIS participants.

In the absence of long-term accommodation, NDIS participants cycle through a succession of unsustainable short-term arrangements. Some OPA guardians face such limited choice within the NDIS market that the safest option is to move a client into a Supported Residential Service (SRS). SRS are not always NDIS providers (issues arise when they are - this is discussed later in this submission) and in both cases, participants risk losing SDA funding to underspend, at the expense of their safety. At its worst, as with the shortage of service providers, the SDA shortage has left participants in unnecessary detention within the criminal justice or mental health systems or has thrust participants into homelessness.

Similar issues arise where, in the absence of available SDA for participants aged over 65 years of age, the only option available to OPA quardians is residential aged care. In these cases, the participant loses their entire NDIS package. This issue is discussed in more detail below.

In these ways, the SDA thin market has far-reaching systemic impacts as it imposes unnecessary strains on adjacent sectors. The Illusion of Choice and Control presents multiple examples of this.

In terms of short-term accommodation, OPA staff report recent improvements since the introduction of processes for OPA, emergency services and hospitals to access contingency providers. However, OPA also holds grave concerns regarding inappropriate short-term placements, in SRS, potentially driven by high vacancy rates in that sector.

There is a particular need for short-term accommodation for clients with complex needs who, for example, ordinarily live in robust SDA, where there has been damage or a natural emergency or damage to the building.

¹² The Summer Foundation, Specialist Disability Accommodation (SDA) in Thin Markets (2021) 3.

¹⁴ National Disability Insurance Scheme, Victoria Quarterly Performance Dashboard 30 June 2022 (20220 ndis.gov.au/about-us/publications/quarterly -reports

¹⁵ United Nations, Concluding Observations: UN Report on Australia's Review of the Convention on the Rights of Persons with Disability (CRPD), 24 September 2019 (2019)11.

Recommendation 15

The National Disability Insurance Agency should publish, consult on and implement its Maintaining Critical Supports and Immediate Support Response policy and framework as a matter of urgency. This policy and framework should ensure that:

- multiple designated providers of last resort are clearly identified;
- providers of last resort are adequately resourced to enable them to respond immediately in situations of market failure which includes having staff available on short notice:
- the providers and their staff have specialised experience, skill and expertise that are relevant to the specific needs of participants;
- clear procedures exist to guide planners, local area coordinators and support coordinators when the need arises for a provider of last resort to provide any approved support (not just 'critical' supports);
- participant plans have built-in flexibility for situations in which a provider of last resort is required, including the ability to access contingency funding:
- as soon as possible, participants are transitioned back to support outside provider of last resort arrangements.

Recommendation 16

The National Disability Insurance Agency as market steward, in collaboration with federal, state and territory governments, should consider the effectiveness of the specialist disability accommodation (SDA) pricing framework under the National Disability Insurance Scheme. The review should consider:

- the availability, diversity, and stability of SDA;
- mapping current SDA and identifying gaps in the market;
- whether clients most in need of SDA are prioritized;
- · ways to stimulate the SDA market;
- robust builds for situations of crises;
- provider of last resort arrangements.

Recommendation 17

The National Disability Insurance Agency, in conjunction with federal, state and territory governments, should adjust market levers and policies (including the pricing framework) to stimulate and ensure the existence of sufficient numbers and diversity of crisis accommodation providers, and should also ensure that sufficient funds are provided so that Specialist Disability Accommodation provision is able to meet existing and future demand.

Recommendation 18

The National Disability Insurance Agency's Maintaining Critical Supports and Immediate Support Response policy and framework should specifically address and provide guidance in relation to Specialist Disability Accommodation and crisis accommodation providers of last resort. The framework should include a vacancy management strategy for providers to prioritise clients with the most urgent need.

Recommendation 19

The National Disability Insurance Agency should enable contingency funding to be immediately accessible when crises arise. This approach would require designated liaison and emergency contact points and procedures within the NDIA (or authorised agencies) which are responsive during and outside of business hours.

Recommendation 20

The National Disability Insurance Agency should directly commission the provision of appropriate Short Term Accommodation and Assistance (STAA) for participants who need accommodation at short notice.

Recommendation 21

The National Disability Insurance Agency should work with federal, state and territory governments to enact legislative and other safeguards to provide security of tenure and other rights protections for all forms of accommodation used by NDIS participants, including people in Specialist Disability Accommodation.

6. Safeguarding

The National Disability Insurance Scheme Act 2013 establishes the role of the NDIS Quality and Safeguards Commission as the agency with the core function of safeguarding NDIS participants, and the legislative framework under which this occurs. While not strictly relevant to capability and culture at the NDIA, OPA would note that safeguards under the NDIS Quality and Safeguards Framework are largely focused on ensuring effective complaints processes and on the 'natural' safeguard of consumer choice. OPA has been vocal about the ways in which this model is problematic for people with cognitive disability, especially those with no informal supports. To summarise, a complaints process requires a (supported) proactive complainant and 'consumer choice' requires a selection of viable service options to be available. These requirements are, in OPA's experience, frequently unmet, especially for people with complex and challenging support needs.

Given these shortfalls in the safeguarding environment, OPA considers it particularly urgent that the NDIA strengthens its own capabilities with respect to the safeguarding of the participants it interacts with through the NDIA's Local Area Coordinator, NDIA Planner, Plan Manager, and Support Coordinator roles. There is significant scope for the NDIA to contribute to improved safety for NDIS participants, as highlighted in recent hearings of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Disability Royal Commission).¹⁶

The situation of Ann Marie Smith who died on 6 April 2020 in what have been described as 'appalling' circumstances after a substantial period of neglect, was illustrative of this. The Disability Royal Commission highlighted three key issues identified by previous inquiries into the circumstances which led to Ms. Smith's death.

Firstly, the Disability Royal Commission highlighted the need to identify circumstances which place a person with disability who receives supports or services at heightened risk and have a process for assessing these circumstances for all NDIS participants.¹⁷ While simply living with a disability in and of itself does not make a person vulnerable, as noted by

¹⁶ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Public Hearing Report, Public hearing 14 Preventing and responding to violence, abuse, neglect and exploitation in disability services (South Australia)* (2021) and <u>Public hearing 26: Homelessness, including experience in boarding houses, hostels and other arrangements | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability</u>

¹⁷ Disability Royal Commission, Report on Public hearing 14

Preventing and responding to violence, abuse, neglect and exploitation in disability services (South Australia) (2020) 59. ('Royal Commission Report')

the Disability Royal Commission having a disability can interact with other circumstances in a person's life (for example, living alone, financial insecurity) that interact with disability in a way that produces vulnerability. Identifying these factors in a person's life which may make them more vulnerable to violence, neglect, and abuse is a critical priority.

The Safeguarding Report produced by the South Australian Safeguarding Taskforce in response to Ms. Smith's death specifically noted that the NDIA should develop a methodology to assess whether participants are at risk of violence, abuse, neglect or exploitation as part of the planning process and put supports in place according to the participant's level of risk.

OPA understands from evidence at a recent hearing before the Disability Royal Commission that the NDIA is identifying participants who may be particularly vulnerable because they have little or no informal support or might have only one provider providing them with services. 18 OPA considers other relevant factors for establishing vulnerability include the person having no next of kin, living alone, or living in supported residential services

Secondly, there needs to be appropriate safeguards (such as regular face-to-face contact with the participant) once a person at heightened risk of abuse or neglect is identified.

In evidence before the Disability Royal Commission the NDIA noted that staff regularly check-in with participants between plan start date and plan end date. 19 However, it is not possible over the phone to ensure that the participant is able to speak freely or to build trust. For these reasons, it is critical that the NDIA ensures face-to-fact contact with participants who have been flagged as vulnerable.

Similarly, a witness appearing at Disability Royal Commission Public Hearing 14 argued that planning sessions should be conducted face-to-face, preferably in the individual's home, noting that this would be more likely to establish trust between the NDIS participant and the planner.20

Finally, information sharing arrangements between state government entities (such as the South Australia Department of Human Services), the NDIA, and the NDIS Quality and Safeguards Commission requires improvement. At Disability Royal Commission Hearing 26, it was reported that NDIS Commission officers have access to the 'vulnerability flags' through the NDIS Commission's operating system.²¹ However, because of the NDIA's legislative framework, the agency is unable to share crucial information about vulnerable NDIS participants with state and territory safeguarding agencies such as OPA, leading to adverse outcomes for NDIS participants. Similarly, if appropriate information sharing arrangements were in place, Community Visitor Programs would be well placed to crosscheck the NDIA's data and potentially flag vulnerable participants with the agency.

Another safeguarding issue concerns provider conflicts of interest when they are providing multiple types of support to a participant - for example, both support coordination and accommodation services. OPA has observed instances of participants receiving both accommodation and core supports from a single agency, which have resulted in adverse outcomes such as poor-quality service provision and participant capture.

While the advocacy role of Community Visitors was acknowledged in the Disability Royal Commission Public Hearing report on Public Hearing 14, OPA considers that the scope of this advocacy is too limited to fully protect the rights of people with disability in group

¹⁸ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Transcript of Proceedings, Public hearing 26, Wednesday, 31 August 2022 (2022) 226.

²⁰ n16 Royal Commission Report 60.

²¹ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Transcript of* Proceedings, Public hearing 26, Friday, 2 September 2022 (2022) 378.

homes. There are also many settings in which NDIS participants live which are not covered by state Community Visitor schemes.

In addition to supporting participants to access the scheme and access the supports that they need (thereby reducing the administrative use of guardianship), independent advocates are well placed to identify participant vulnerability, whether a participant has been manipulated to use their plan in a particular way and fraud. In the absence of funded case management or advocacy, there is no independent monitoring to ensure that the rights of participants are upheld and that they are receiving the services that they need (noting that, at least in some circumstances, the NDIA does not currently have mechanisms in place to ensure that, at minimum, a participant has received the services that have been paid for out of their package).²²

As discussed previously with respect to supported decision-making, independent advocacy plays an important role in protecting the rights of people with disability in many contexts, and there is a valuable opportunity to introduce independent advocacy, funded by the NDIA, into the role of Decision-Supporter that the NDIA is currently developing.

Recommendation 22

The National Disability Insurance Agency and the NDIS Quality and Safeguards Commission should consult with relevant stakeholders and the broader community on the scope of its Vulnerable Participants Framework and about the process for working with participants who are identified as vulnerable, to ensure it offers them adequate protection from violence, abuse, and neglect in the context of NDIS service delivery.

Recommendation 23

The National Disability Insurance Agency should put in place a policy that support coordinators should ordinarily be independent of a participant's accommodation and core support providers.

7. Lack of transparency and focus on financial sustainability

The *National Disability Insurance Scheme Act 2013* is reflective of market principles – the objects of the Act (Section 3) include enabling people with disability to exercise choice and control, supporting economic participation, and promoting high-quality and innovating supports (amongst others) through the provision of an insurance-based approach, informed by actuarial analysis. The Act mandates that in giving effect to these objects, 'regard is to be had to: a. the need to ensure the financial sustainability of the NDIS' (Subsection 3). These underlying principles have significant implications for the culture of the NDIA and the provision of support through the NDIS more broadly. OPA observes three key issues with these policy objectives and the practises that arise from them.

First, there is a risk that those making decisions under the act will not recognise that financial sustainability needs to be considered in the broader context of the economic impact of the scheme. One recent study found that the economic impact of the scheme is likely to be very large, even compared to other types of government spending. A conservative estimate of the multiplier effect of the NDIS is in the range of 2.25. The NDIS is therefore estimated in 2020-21 to produce economic activity in the region of \$29 billion in addition to that created by the \$23.3 billion of NDIS spending; a total of \$52.4 billion.²³

²² Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Transcript of Proceedings, Public hearing 26, Wednesday, 31 August 2022* (2022) 242.

Per Capita, False Economy: The economic benefits of the NDIS and the consequences of government cost-cutting (2021) https://percapita.org.au/our work/false-economy-the-economic-benefits-of-the-ndis-and-the-consequences-of-government-cost-cutting/

Other insurance-based schemes such as the Transport Accident Commission (TAC) and Workcover take a financial sustainability across the lifetime approach. The NDIA does not have data to inform such an approach and therefore takes a short term, plan by plan approach to financial sustainability. Rather than ensuring the long-term financial sustainability of the scheme, this approach risks cost blowouts in the longer term at the expense of participant safety and wellbeing.

Secondly, the focus on financial sustainability in individual decision making can result in inequity for participants. One example of this is the inequity that stems from the need for a participants and potential participants to fund their own assessments. Participants who have a TAC package or other independent means can pay the cost themselves and, consequently, receive and implement their NDIS plan earlier than those who need an additional plan review to get to the same point. The planning process can be delayed by at least two months, often much longer if the participant is required to await a plan review to receive funding for the necessary and reasonable supports identified in the assessment. Section 16 of the NDIS Act states that 'the Agency may provide support and assistance to people in relation to doing things under, or for the purposes of, this Chapter'. OPA recommends this section be amended to explicitly include financial support as a form of support that the Agency provides.

In some cases, participants received less funding and consequently fewer services under the NDIS than they did under the previous funding model (i.e. DHHS Individual Support Package). As previously explained, this is likely due, in part, to failures of planners (or delegates of the CEO) to accept professional advice around complex needs, as well as a perceived pressure to keep NDIS costs low and sustainable. In other cases, OPA delegated guardians have seen initial participant plans purposely limited with a focus on getting a support coordinator in place to prepare and make the case for a subsequent, more sizeable plan.

OPA finds that many people with complex and challenging support needs do eventually obtain substantial NDIS funding. In some cases, planners work with the OPA guardian to obtain necessary evidence to ensure that the participant receives the supports that they need. In other cases, obtaining approval for adequate, ongoing funding sometimes only occurs after significant external pressure is applied by a guardian, the media and/or a court, or following an often-predictable crisis (sometimes at great cost to the participant). When more significant plans are approved, the Agency is clear on its expectation that the increased funding is temporary and the support models will have to be scaled back, in line with the insurance model of the scheme.

OPA delegated guardians have multiple examples of discrepancies in participant plans. In *The Illusion of Choice and Control*, OPA told the story of Yasmin who received a plan that was \$200,000 (64 per cent) smaller than the quotes provided in the planning meeting, without any justification being provided by, the Agency. This lack of decision-making transparency, which is compounded by the failure of the decision-maker to give clear reasons for any refusals or discrepancies in funding, makes it difficult to understand the basis of decisions and to advocate effectively on the participant's behalf.

Equally frustrating is the lack of clarity regarding who within the Agency actually makes the decision regarding plan approval. In some cases, OPA delegated guardians experience positive planning meetings where the planner seemed to grasp what was required, but then the approved plan was returned inexplicably smaller.

Providing more detailed information about planning discrepancies, and providing draft plans before plans are finalised, would provide welcome transparency and may lead to fewer plan reviews and appeals. Providing sufficient detail increases the capacity of people involved in the planning process to improve future plans, facilitates advocacy, and improves options to adequately support participants.

Recommendation 24

Section 16 of the *NDIS Act 2013* should be amended to state that the National Disability Insurance Agency may fund any assessment that is requested or required in the preparation of a plan or as part of a plan review.

Recommendation 25

The *NDIS Act 2013* should be amended to require the National Disability Insurance Agency to provide written reasons in an accessible format, on request from a participant or person acting on their behalf, regarding discrepancies between requested and approved supports.

8. Expert Assessment vs 'value for money'

OPA has concerns about planners (or other delegates of the CEO) refuting and misinterpreting clinical assessments when deciding which supports ultimately get funded in a participant plan. Assessments are typically written using a health care paradigm or framework, but in the NDIS context are interpreted by planners who are looking to, appropriately, match clinical recommendations to administrative or legislative requirements. Planners may not have sufficient clinical expertise to interpret whether the report meets the funding criteria. As a result, health services have reported that they must often edit the assessments to mimic the Agency's preferred terminology, compromising clinical precision. For instance, one hospital worker submitted a patient assessment in respect of permanent repercussions associated with a stroke, which was refuted by the Agency as not meeting the NDIS' disability requirement. The practitioner amended and re-submitted the assessment relating the same clinical presentation as an Acquired Brain Injury (which, while clinically correct, is less precise) and this was accepted. This administrative back and forth delays service delivery and imposes unnecessary work on health care practitioners.

In practice, there seems to be an unfavourable attitude or culture among Agency staff that participants request overly costly supports and equipment, negating the expertise of clinical assessors. OPA queries whether planners are sufficiently trained to refute clinical advice. It may be the case that the Agency enlists technical expertise to assist with more complex matters, but the consultation is usually confined within the Agency rather than occurring collaboratively with the participant and their supporters. Ultimately, if a health or allied health professional makes a recommendation, it should be accepted as a 'reasonable and necessary' support.

In practice, OPA has found that historically, the tension between the first two criteria (i.e. value for money versus expert opinion) is often resolved by the Agency by giving disproportionate weight to safeguarding the financial viability of the scheme, without a full exploration of all available options and sometimes, to the detriment of a participant's wellbeing. An emphasis on short term financial savings compromises both the participant and, arguably, the scheme by increasing costs in the long term. OPA Advocate Guardians and Community Visitors have recently observed that these two competing priorities are increasingly being rebalanced towards favouring expert opinion, with staff reporting that they are experiencing fewer issues with clinician-identified supports being fully funded. However, there is still some way to go before it can be said that all participants are receiving reasonable and necessary supports.