Office of the Public Advocate

Safeguarding the rights and interests of people with disability

Submission to the Joint Standing Committee on the NDIS

Inquiry on planning

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Dr Colleen Pearce
Public Advocate
Office of the Public Advocate

Dr John Chesterman
03 9603 9567
John.Chesterman@justice.vic.gov.au

Office of the Public Advocate
Level 1, 204 Lygon Street, Carlton, Victoria, 3053
Tel: 1300 309 337
www.publicadvocate.vic.gov.au

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The Department of Social Services and the National Disability Insurance Agency should urgently develop and publicly release a plan outlining how assertive outreach services will be delivered to ensure people with disability who are hard-to reach can effectively engage with the NDIS and / or other support programs.

The strategy should explicitly identify high priority groups, including residents in congregate care settings and individuals in the criminal justice system.

Recommendation 2

The Council of Australian Governments (COAG) Disability Reform Council should direct State and territory governments to develop a Disability Justice Strategy, as proposed in the Australian Human Rights Commission report *Equal before the law*.

The Strategy should identify in a deliberate and standardised way:

- a well-defined method for identifying and screening prisoners with a cognitive disability, including acquired brain injury and mental illness, upon reception;
- a timetable to guide the assessment of existing prisoners;
- whether people entering custody are NDIS participants or potentially eligible to be so;
- who is responsible for informing prisoners about the NDIS;
- who will assist a prisoner to complete an access request;
- who will assist with planning discussions and what training that person requires.

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The National Disability Insurance Agency should provide reasonable accommodations at the point of access to the scheme to give effect to its legislative obligation that people should wherever possible be provided with the support to make and implement their own decisions.

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The National Disability Insurance Agency should, in its review of the New Starter Program, ensure that all planners and Local Area Coordinators (LAC) have the skills necessary to support and work with persons with cognitive impairment.

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The National Disability Insurance Agency should develop a streamlined process for eligible participants to enter the Complex Support Needs Pathway, from the point of access to the scheme.

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The National Disability Insurance Agency should ensure Local Area Coordinators (LACs) are adequately resourced to fulfil their role, including linking participants to NDIS and mainstream and community supports.

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The Victorian Department of Health and Human Services, and equivalent state and territory departments, should:

- continue to operate the Intensive Support Team (in Victoria) and similar programs;
- provide ongoing case management for participants with complex and challenging support needs where this is required.

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The Council of Australian Governments (COAG) Disability Reform Council should review the *Principles to Determine the Responsibilities of the NDIS and Other Service Systems* to ensure they provide clear guidance to resolve interface questions.

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The National Disability Insurance Agency should provide clear breakdowns and descriptions of the specific supports to be provided under each line item in participant plans. Where the amount of funding is significant, more detailed breakdowns should be provided.

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

Recommendation 16

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.

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.[1]

The Public Advocate is appointed by the Governor in Council and is answerable to the Victorian Parliament. OPA's primary functions include advocacy, investigation, and guardianship services for people with cognitive impairment and mental illness. The Office provides advice, information, and education about laws affecting people with disability and coordinates four volunteer programs.

Last financial year, OPA was involved in 1806 guardianship matters (963 of which were new), 389 investigations, and 320 cases requiring advocacy.

In 2017-18, the Public Advocate was guardian for 182 NDIS participants, advocate for 13 participants, and OPA undertook 28 investigations in relation to individuals where NDIS matters were relevant. OPA has acted as an advocate for 57 participants who currently reside or have previously resided in Colanda Residential Services and Disability Accommodation Services in Colac and Geelong during the NDIS trial phase.

OPA provides training and support to more than 600 volunteers across four volunteer programs: the Community Visitors Program, the Community Guardian Program, the Independent Third Person Program, and the Corrections Independent Support Officer Program. As a key component of the quality and safeguarding arrangements operating during the transition to the NDIS, OPA Community Visitors continue to visit disability residential accommodations, supported residential services, and mental health facilities where residents and patients have various interactions with the NDIS.

OPA continues to undertake a range of systemic advocacy activities in the transition to the NDIS and the implementation of a nationally consistent quality and safeguarding framework. OPA has prepared submissions to past inquiries led by the Joint Standing Committee on the NDIS (the Committee) and welcomes the opportunity to make a submission in relation to planning.

OPA appreciates the continued engagement of the Committee and recognises the efforts that the NDIA and Commonwealth and State/Territory Governments have made to implement some of the Committee's recommendations. While the NDIS has great potential to provide choice and control to people with disability, OPA notes that this intention has not yet been realised and the scheme continues to disadvantage people with cognitive impairment. OPA welcomes the opportunity to contribute to this inquiry.

2. Access

While this inquiry focuses on planning, there are significant barriers that can prevent prospective participants from accessing the scheme and reaching the planning stage.

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[1] *Guardianship & Administration Act 1986* (Vic).

2.1. Outreach to priority groups

In its submission to the Committee’s inquiry on market readiness, OPA stressed the importance of outreach in the context of the NDIS roll out:

> “Initial engagement with the scheme can be demanding for participants who have limited informal supports in their lives, who may be isolated, or who have no access to independent advocacy. This is further complicated where the participant has a cognitive impairment or when there is uncertainty around the capacity of the person to consent to accessing the scheme and little support available to enable access.
>
> Community Visitors are in a unique position to observe and report from the frontline about the implementation of the NDIS for people with a cognitive impairment or mental illness. They have documented instances in which individuals have not been able to access the advocacy necessary to enable them to participate in the scheme, particularly if they have no circle of support other than paid workers. Community Visitors report that the NDIS application process can be complex and potential participants may find it challenging to work through it without assistance. Their reports from NDIS roll out areas highlight that many of the residents they visit are struggling to understand, adapt to, integrate, and navigate the new market.”

In many circumstances, these observations, which now date back a few years, still hold true. OPA appreciates the Committee’s recognition of the need for assertive outreach and welcomes the recommendation made to this effect in its report on the inquiry into transitional arrangements for the NDIS:

> “The committee recommends the Department of Social Services and the NDIA develop and publicly release a plan outlining how assertive outreach services will be delivered beyond transition to ensure people with disability who are hard-to reach can effectively engage with the NDIS and / or other support programs.”[2]

In the government response to the Committee’s report and recommendations, the Australian Government alluded to a *Hard to Reach Strategy*, which was scheduled for release in 2018, that would purportedly align with the Complex Support Needs Pathway.

OPA notes that the pathway is in full roll out yet the overarching *Hard to Reach Strategy* has, to OPA’s knowledge, never been made public. The Complex Support Needs Pathway represents only one of many strategies that will be required to engage with ‘hard to reach’ groups but, in and of itself, does not constitute a comprehensive outreach strategy. Although the Complex Support Needs Pathway, in its conception, focused on ‘hard to reach’ clients that were known to state based disability services, it is now essential to identify and extend outreach to individuals who may not be known to disability services and are new to the sector. OPA repeats and endorses the Committee’s recommendation and urges its implementation.

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[2] Joint Standing Committee on the National Disability Insurance Scheme. *Report on transitional arrangements for the NDIS.* (February 2018) xiii.

Recommendation 1

The Department of Social Services and the National Disability Insurance Agency should urgently develop and publicly release a plan outlining how assertive outreach services will be delivered to ensure people with disability who are hard-to reach can effectively engage with the NDIS and / or other support programs.

The strategy should explicitly identify high priority groups, including residents in congregate care settings and individuals in the criminal justice system.

The barriers faced by these cohorts in accessing the scheme are unique and assert that any outreach to these groups requires a tailored approach.

Residents in congregate care (Supported Residential Services in Victoria)

Supported Residential Services (SRS) in Victoria are privately operated residences that provide accommodation and support for individuals who need assistance with everyday activities. There are 3,983 registered SRS beds[3] across the state with each SRS differing in services, resident profiles, and fees. Similar facilities exist in other jurisdictions, such as Licensed Boarding Houses in NSW, psychiatric hostels in WA, Supported Residential Facilities in SA, and Boarding Houses and Hostels in QLD.[4]

SRS residents have varying levels of support needs; most have health conditions that require some level of daily care and the majority (91 per cent) have a disability.[5] In OPA's experience, the SRS sector is often asked to fill the gap left in the absence of community-based accommodation for people with disability and mental illness.

SRS operate with many of the hallmarks of institutions and SRS residents remain one of the most marginalised groups of people. It is estimated that around half of SRS residents do not receive independent funding or support outside of the facility.[6] Facilities offer limited privacy and independence, usually housing between 20 to 80 residents. Staff to resident ratios are low and the training requirements for staff are minimal. Consequently, the SRS model is focused on personal care and does not provide rehabilitation or specialist supports.

In Victoria, Community Visitors are legislated under the *Supported Residential Services (Private Proprietors) Act 2010* (Vic) to make visits, both announced and unannounced, to SRS to make enquiries of residents and staff and examine selected documentation in relation to the care of residents.

Community Visitors have long documented their concerns around access to the NDIS for SRS residents since the commencement of roll out. According to 2018 data, only sixteen per cent of all SRS residents have an NDIS package,[7] although this figure rises to 51 per cent when focusing on a sample of residents under the age of 65.[8] Nonetheless, the figure

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[3] Department of Health and Human Services (Vic), *Supported Residential Services Census 2018* (2018).
[4] Private Congregate Care (PCC) Alliance. *People with psychosocial disability living in Supported Residential Services (SRS): Submission to the mental health Royal Commission* (2019).
[5] Department of Health and Human Services (Vic), *Supported Residential Services Census 2013* (2013) 58.
[6] Idem.
[7] Department of Health and Human Services (Vic), *Supported Residential Services Census 2018* (2018).
[8] Preliminary data from the Community Visitor SRS NDIS Survey 2018-19. This data will appear in the Community Visitors Annual Report 2018-19, which will be published once it is tabled in parliament.

varies according to individual facilities, ranging from 18 to 95 per cent of eligible residents within the one SRS having an NDIS plan.

Many SRS residents do not have informal networks to support them in the NDIS process. This means that they rely on SRS staff who do not always have the understanding or resources to assist with the lengthy process. For SRS proprietors, facilitating access to the NDIS is sometimes clouded by a misunderstanding of the scheme. For example, Community Visitors note that some proprietors fear losing residents to the scheme. Other proprietors have chosen to register as NDIS providers, predominantly in the category of Supported Independent Living (SIL) supports. This creates the potential for a conflict of interest and complicates regulation, as SRS in these situations would hold dual registration under the Victorian SRS Act to provide accommodation and support and the federal NDIS Act to provide similar or like supports. OPA expands on this issue in its submission to this Committee's concurrent inquiry on Supported Independent Living.

Community Visitors have also observed that some SRS residents have been declined access to the scheme for a variety of reasons, the most common being an inadequate or incomplete application.

The NDIA has acknowledged that SRS residents qualify as a 'hard to reach' group yet outreach into this sector thus far has been limited to initiatives led by state and community-based organisations rather than the NDIA. OPA expects the same to be true in congregate care settings in other jurisdictions.

One such initiative is the SRS Resident Opportunities After Reform (ROAR) project, a partnership of community service organisations that was implemented in the eastern metropolitan Melbourne area. The program prepared SRS staff for NDIS access and planning processes and assisted residents to articulate their support needs. In addition, the ROAR project facilitated access to My Aged Care packages for SRS residents over 65 years of age. The ROAR project was an overwhelming success with many residents aided to receive additional supports. OPA is aware of initiatives similar to ROAR in other jurisdictions but without an overarching strategy guiding these efforts, there is a risk that some potential participants will be left behind. Community Visitors and OPA would like to see a similar initiative extended state-wide to all SRS[9] and into similar congregate care settings across Australia.

Recommendation 1 builds upon a recommendation made by Community Visitors in their 2017-18 annual report for assertive outreach into all similar congregate care facilities in Australia to enable residents to access the NDIS.

People in custody in the criminal justice system

It is well known that people with cognitive impairment are over represented in the criminal justice system, yet detention facilities (at least in Victoria) are not consistently facilitating NDIS access requests for the people they are supporting and responsible for. Delays in accessing disability supports can contribute to people entering, remaining, or cycling back into detention because of risks arising from unmet support needs. The costs to the

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[9] Community Visitors *Annual Report* (2017-18).

individual are detrimental, sometimes devastating, as are the costs to the human service system.

OPA has a long history of advocating for procedures to be put in place to systematically identify and screen prisoners who may have a cognitive impairment as they enter custody. It is disturbing that this has not yet been recognised and implemented as best practice. Rather, individuals who are detained often are not made aware of how and where they could access or undertake disability assessments. In relation to the NDIS, to OPA's knowledge, no standard triggers exist to assist people in custody to make an access request, seek a plan review, or even to test their eligibility for the scheme.

Even if a prisoner is aware of, and seeks to access the NDIS, the absence of a procedure and associated training for staff means that prisoners do not receive the support that they need and are entitled to. For example, a private prison social worker advised an OPA delegated guardian that they could not assist a participant with accessing the scheme, claiming that sharing information with the NDIA would consist a breach of the prisoner's privacy.

The absence of a clear process to enable access to the NDIS and other disability supports for people in custody has real consequences for potential participants. When no access request is made, follow up is unlikely to be taken up by other arms of governments, leading to further delays in access and planning processes. This could, but has not yet, easily be integrated into pre-release planning.

OPA in partnership with Victoria Legal Aid (VLA) and the Australian Federation of Disability Organisations (AFDO) briefed senior government officials and the NDIA on this matter. The briefing presented seven real client stories that exemplified critical points of confusion at the interface of the NDIS and the criminal justice system. These interface issues can have an impact on whether a person can access the scheme and / or receive funding for NDIS supports while in custody (whether on remand or during their sentence).

The Australian Human Rights Commission's (AHRC) *Equal Before the Law* report (2014) is a significant document for people with disability and all Australians. In conducting its research and consultation, the AHRC heard stories of where the criminal justice system had failed people with disabilities and had compounded disadvantage, in addition to some positive examples of where best practice was occurring.[10] The report proposed possible actions towards the development of a state or territory administered disability justice strategy as a beneficial approach to address some of the inequities faced by people with disability. The AHRC recommended the development of a Disability Justice Strategy to reduce the number of people with disability and/or mental illness who are incarcerated due to inadequate support for their needs. OPA endorses this recommendation.

Recommendation 2

The Council of Australian Governments Disability Reform Council should direct State and territory governments to develop a Disability Justice Strategy, as proposed in the Australian Human Rights Commission report *Equal before the law*.

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[10] Australian Human Rights Commission, *Equal Before the Law* (2014).

The Strategy should identify in a deliberate and standardised way:

- **a well-defined method for identifying and screening prisoners with a cognitive disability, including acquired brain injury and mental illness, upon reception;**
- **a timetable to guide the assessment of existing prisoners;**
- **whether people entering custody are NDIS participants or potentially eligible to be so;**
- **who is responsible for informing prisoners about the NDIS;**
- **who will assist a prisoner to complete an access request;**
- **who will assist with planning discussions and what training that person requires.**

2.2. Access Request Forms

Any prospective NDIS participant must test their eligibility for the scheme through an Access Request Form (ARF). The NDIA requires an ARF to be signed, ideally by the prospective participant themselves. The NDIA cannot sign an ARF for a potential participant but other forms of support can and should be provided to assist with this administrative task. Where a potential participant has a significant cognitive disability and is unable to sign the ARF, reasonable adjustments should be undertaken to obtain verification from them by other means, for example, by using alternative communication methods.[11]

When a potential participant cannot sign an ARF, the NDIA is prepared to accept an ARF signed on behalf of a potential participant by a supporter or an advocate. Where appointed, a guardian, administrator/financial manager, or attorney with relevant authority can sign an ARF on behalf of a potential participant. NDIA policies also permit a person to make a verbal access request,[12] although OPA is aware that this option is not routinely offered to prospective participants.

In one case, the Public Advocate was guardian of a person who had capacity to request access to the NDIS but could not physically sign the ARF due to the nature of her disability. She could, when provided with adequate support to do so, verbally communicate her wishes and preferences, including her desire to enter the scheme. The potential participant's delegated guardian assisted with the completion of the ARF but the NDIA would not allow verbal consent from the prospective participant to the ARF and instead required the delegated guarding to sign. In this telling example, a seemingly minor procedural task led to an avoidable restriction on a participant's right to exercise their decision-making capacity.

The NDIA is prepared to accept an ARF signed by a service provider on behalf of a potential participant if there is no conflict of interest.[13] This is another area of contention for OPA as the NDIA does not always recognise the role of healthcare professionals and allied health practitioners in supporting potential participants to access the scheme. OPA delegated guardians observe that, in some instances, the NDIA has refused ARFs signed by a hospital healthcare professional, claiming a conflict of interest. Hospital-based healthcare providers are funded separately to the NDIS and therefore should not be in conflict with the scheme. Hospital staff have a role and indeed a duty of care to ensure a

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[11] Office of the Public Advocate (Vic) *Guide to decision making in the NDIS: When a decision can be made by, with, or for an adult with significant cognitive disability* (2018).

[12] https://www.ndis.gov.au/how-apply-ndis/what-access-request-form

[13] Idem.

patient is adequately prepared for discharge, a process that includes connecting them to the necessary community-based services. Arguably, discharge planning includes facilitating access to the NDIS.

OPA is concerned that in an increasing number of cases, as in the examples presented above, the NDIA is requesting guardianship appointments for the sole purpose of signing an ARF on behalf of a participant. This is as an instrumental use of guardianship in the optic of administrative efficiency and is misaligned with the legislative intent of guardianship. While it is true that a guardian with relevant authority may sign an ARF, guardianship should remain importantly a measure of last resort.[14]

In Victoria, the *Guardianship and Administration Act 1986* (Vic) prescribes that, when determining whether or not a person is in need of a guardian, the Victorian Civil and Administrative Tribunal (VCAT) must consider, among other considerations, "whether the needs of the person in respect of whom the application is made could be met by other means less restrictive of the person's freedom of decision and action"[15]. Guardianship legislation in other jurisdictions replicate this provision. In Victoria again, the new *Guardianship and Administration Act 2018* (Vic) will legislate the presumption that a person has decision-making capacity if the person can make decision with support. In the case presented above, the potential participant had capacity to make and communicate her decision when provided with an alternative consent method. Requests for guardianship or requests made of guardians by the NDIA in these circumstances deny participants their right to have control of decisions that affect their lives where they have capacity to do so.

OPA considers that reasonable accommodations need to be provided by the NDIA at the stage of access. This would reduce unnecessary administrative burdens and delays. More importantly, it would give effect to Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and more meaningfully implement the principles of the NDIS Act.

Recommendation 3

The National Disability Insurance Agency should provide reasonable accommodations at the point of access to the scheme to give effect to its legislative obligation that people should wherever possible be provided with the support to make and implement their own decisions.

3. The experience, expertise, and qualifications of planners

OPA staff observe variability in the experience, expertise, and qualifications of planners. 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 approach the task with a more superficial knowledge base and as a result, are less precise in their suggestions. The level of expertise of the planner appointed to any one participant is seemingly determined by chance outside of the Complex Support Needs Pathway, which leads to noticeable inequities for participants.

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[14] In Victoria: *Guardianship and Administration Act 1986*, s22.

[15] Idem.

Inconsistency in the expertise of planners is directly correlated to the quality of the plans that are then provided. OPA notices that participants who have the ability to self-advocate or participants who have a network of supports to assist during planning will generally receive better quality plans. The NDIS consumer directed model does, by nature and design, place an onus on participants to independently navigate through the different stages of the scheme. This is not a straightforward task, as the Committee would have heard in its inquiry on market readiness, and OPA queries whether the induction training for planners is sufficiently developed in this regard.

OPA also observes discrepancies in the level of skill of Local Area Coordinators (LACs) in comparison to NDIA appointed planners. That being said, the LAC model, in which LACs provide ‘grassroots support’, is good in theory and one that should be further developed and adequately resourced. OPA speaks to this in section 4.2 below.

OPA recently published a report entitled *NDIS service agreements: Making choice and control more real*, in which one of the recommendations addressed shortfalls in the training provided to planners and LACs. The NDIA, in its response to the report, stated that:

> “From an internal training perspective, the NDIA is currently reviewing its New Starter Program to ensure the NDIA continuously enhance the way we upskill our Planners and Local Area Coordinators (LACs). Work is also continuing with Disability Advocacy Network of Australia (DANA) to finalise in-depth disability awareness training for Planners and LACs with a stronger focus on human rights and the social model of disability. This includes development of an introductory eLearning module following extensive consultation with DANA and other peak bodies.”[16]

OPA supports the NDIA undertaking this work and will monitor the impact of the subsequent training on the quality of the plans participants receive.

Recommendation 4

The National Disability Insurance Agency should, in its review of the New Starter Program, ensure that all planners and Local Area Coordinators (LAC) have the skills necessary to support and work with persons with cognitive impairment.

4. The ability of planners to understand and address complex needs

OPA acknowledges the continued attention from the NDIA and all levels of government to address barriers to interacting with the scheme for people with cognitive disability and/or limited or no informal supports in their lives. In this section, OPA comments on the ability of planners to understand and address complex needs.

4.1. Complex Support Needs Pathway

The implementation of the Complex Supports Needs Pathway is an encouraging development; it is now fully rolled out and available across Victoria, although OPA is aware

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[16] Office of the Public Advocate (Vic) *NDIS service agreements: Making choice and control more real* (2019) 23.

that this is not yet the case in other States and Territories. OPA hopes the NDIA will publicly report on an evaluation of the pathway.

The NDIA's definition for 'complex support needs' includes the involvement of a participant in multiple service systems including among others, guardianship, mental health, and criminal justice. Therefore, the Complex Support Needs Pathway is, by definition, directly relevant to a significant proportion of OPA's guardianship clients.

OPA advocated for the establishment of the pathway and developed a working relationship with senior NDIA staff in the earlier stages of its implementation. This level of engagement is most welcome, but unfortunately has not resulted in a streamlined process for eligible OPA clients to access the pathway. OPA delegated guardians often report that persistent advocacy is required to enter the pathway. It is sometimes still necessary for OPA staff to escalate the issue to senior NDIA staff, which further delays planning.

Recommendation 5

The National Disability Insurance Agency should develop a streamlined process for eligible participants to enter the Complex Support Needs Pathway, from the point of access to the scheme.

Notwithstanding access issues, the Complex Support Needs Pathway is overall a very welcome initiative that has led to better outcomes for participants for a number of reasons.

Firstly, planners in the pathway are typically specialised and have usually worked in the disability sector, which facilitates planning and importantly contributes to better outcomes for participants. Planners have a good grasp on the broader web of supports required and thus recognise the importance of liaising with other agencies engaged in the care of participants. For instance, planners will attend case coordination meetings organised by other services, allowing them to gain a more holistic understanding of the participant's support needs. The impact of this, however, has been a shrinking of the planner talent pool outside the pathway.

In most cases, plans developed through the pathway result in the appointment of a specialised support coordinator. This is essential to ensure that participants who have complex needs receive the supports that they are entitled to. For this reason, support coordination should be recognised as the foundation for a successful plan. Specialised support coordination is a good starting point and OPA is pleased to see a small number of innovative and expert support coordinators emerge within the NDIS market. Nonetheless, the support coordination workforce is not yet fully or sufficiently developed and there remains considerable variability in the level of skill and availability of specialists in this field.

Finally, the shorter timelines and flexibility of plans developed through the Complex Support Needs Pathway are promising features. Plans developed through the pathway are, on average, delivered within shorter time frames (i.e. usually within one week as opposed to within two to six weeks in the 'regular' pathway). One of the most well received characteristics of the pathway is the built-in flexibility of plans, whereby the allocated funding for any given line item can be adjusted by the planner without having to undergo a full plan review. This is informed through the continuous engagement between planner and support coordinator and is possible because of the authority bestowed upon planners to make funding adjustments. The flexibility significantly reduces administrative hurdles and delays, providing participants with NDIS plans that are genuinely responsive to changing circumstances and fluctuating needs. OPA advocates in section 6 for this feature to be available to all NDIS participants.

4.2. Case management

Without diminishing the significant improvements brought about by the Complex Support Needs Pathway, there is a noticeable service gap emerging that was previously filled by case management. Case management is a holistic approach to the coordination of multiple aspects of a person's care and life. Case managers provide direct support to coordinate service provision across sectors and service systems with the objective of maximising the expected outcomes for the client.

Previously in Victoria, case management was funded in Individual Support Plans (ISP) to allow, for example, psychologists to attend case conferences or provide updated risk assessments to service providers. In the NDIS model, case management across sectors is not explicitly funded, which can hinder the effectiveness of multidisciplinary care. For instance, the NDIS does not fund care team communication, information sharing, or training.[17]

The *Principles to Determine the Responsibilities of the NDIS and Other Service Systems* state that "the interactions of people with disability with the NDIS and other service systems should be as seamless as possible". [18] Yet, the detailed tables of funding responsibilities presented in that same document prevent the appointment of a role like that of a case manager in an NDIS plan. This is because roles and responsibilities are organised according to funding priorities rather than being guided by the broader needs of persons with disability.

In some policy directives, the NDIA suggests that LACs and support coordinators have a role in connecting participants to 'community, mainstream and other government agencies', but in practice OPA has observed that, until now, planners, LACs, and support coordinators are limited in their activities to the remit of supports funded in an NDIS plan.

Furthermore, OPA highlighted, in its submission to this Committee's inquiry into transitional issues, that planners, LACs and support coordinators are not responsible for communication between providers. The result is a loss of wrap around care, as in the following example where Community Visitors were made aware that an NDIS participant was banned from a shared bus that would transport residents to a day program. The transport service provider banned him for behaviours of concern that made the other residents on the bus feel unsafe. The provider, however, failed to provide notice or to inform the SIL provider who could have supported him with behaviour management strategies to enable him to continue his day program.

Thus far in the transition to the NDIS, guardians (which, it bears repeating, are appointed as a measure of last resort) have often been left to fill the case management role, despite this not being one of their legislated roles. To this point, OPA delegated guardians find that a great deal of advocacy is required on behalf of their clients who are NDIS participants; they record 60 to 70 per cent more 'actions' for clients in the scheme compared to other

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[17] Office of the Public Advocate (Vic) *The Illusion of Choice and Control* (2018) 19.

[18] Council of Australian Governments *Principles to determine the responsibilities of the NDIS and other service* systems (November 2015) 1.

guardianship matters. It also appears that guardianship orders are sometimes being made or renewed by VCAT to ensure that there is someone to fulfil a coordination and oversight role when things are not going well, which is not necessarily an appropriate use of guardianship, particularly when no decisions need to be made.[19]

In Victoria, the Department of Health and Human Services has been responsive by maintaining a residual case management like role through various programs such as the Intensive Support Team (IST) and the Multiple And Complex Needs Initiative (MACNI).

To be eligible for MACNI, a person must satisfy two or more of the following: mental illness, acquired brain injury, intellectual impairment, severe substance dependence, as well as exhibit ‘violent or dangerous behaviours’. The MACNI Framework prescribes “intensive supervision and support and would derive benefit from receiving co-ordinated services in accordance with a care plan that may include welfare services, health services, mental health services, disability services, drug and alcohol treatment services or housing and support services.”[20]

The majority of clients in the MACNI program are eligible for the NDIS, which is unsurprising given the overlap in eligibility criteria. In OPA’s experience, MACNI clients can usually enter the scheme through the Complex Support Needs Pathway and receive specialised support coordination, yet these clients still benefit from having a MACNI case manager to oversee their care more comprehensively.

Case management like that provided by MACNI is crucial in the lives of people with complex needs. For example, one OPA guardianship client was supported by her MACNI case manager to obtain public housing in her name. The impact of this on her disability related needs and her overall wellbeing was significant. Having secured public housing means that while she may cycle into mental health care or custody, she will retain a fixed address to be bailed into and will avoid unnecessary detention for lack of available accommodation.

State based wrap around services like MACNI and the IST are only available to participants with complex needs, are difficult to access, and, in the case of the IST is only available for short durations at times of crisis.

Some OPA clients have been turned back from MACNI on the basis that MACNI coordination would be duplicating service that could be funded in an NDIS plan. In one case, MACNI advised OPA that a participant’s NDIS specialist service coordination should ensure effective monitoring of the client’s care (e.g. by managing future admissions and discharges to hospital). MACNI attended the client’s NDIS planning meeting to make recommendations to that effect, but the NDIA has not yet approved the funding requests.

More concerning is that the future of services like MACNI and IST is undetermined. In a strictly financial sense, case management is compatible with the insurance model of the scheme, whereby a person’s needs are addressed as a whole, in the hope of increasing their independence and wellbeing and reducing their reliance on social services.

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[19] Office of the Public Advocate (Vic) *The Illusion of Choice and Control* (2018) 32.

[20] Department of Health and Human Services (Vic) *Service provision framework: Multiple and Complex Needs Initiative* (December 2017).

As previously mentioned, the specialist support coordination workforce is developing. Some specialist support coordinators bring sufficient skill, experience, and knowledge to undertake their role in a comprehensive manner. OPA is encouraged to see some support coordinators interpret their role more holistically by assisting to connect participants to health or housing supports, for example. However, the situation remains that 'case management' as it was once known is not explicitly funded within the current structure of NDIS plans and, consequently, not replicated in the support coordination service model.

With regards to LACs, OPA appreciates that every NDIS participant is allocated a LAC. However, with the pressure to meet roll out targets, LACs have necessarily focused on planning tasks, neglecting the community linkage component of their role. OPA hopes this is a transitional issue that will subside now that Australia has reached full scheme.

Recommendation 6

The National Disability Insurance Agency should ensure Local Area Coordinators (LACs) are adequately resourced to fulfil their role, including linking participants to NDIS and mainstream and community supports.

OPA refers to a recommendation made in its report *The Illusion of Choice and Control*, which, while specific to the Victorian context, would be applicable in other jurisdictions where participants are likely to benefit from similar service safety nets.

Recommendation 7

The Victorian Department of Health and Human Services, and equivalent state and territory departments, should:

- **continue to operate the Intensive Support Team (in Victoria) and similar programs;**
- **provide ongoing case management for participants with complex and challenging support needs where this is required.**

4.3. Interface principles

Participants with complex needs often receive services across multiple systems and it is expected there will be some crossover between supports. In these cases, planners have a key role in determining which supports will be funded through the NDIS and which will fall to other sectors. In doing so, planners apply the *Principles to Determine the Responsibilities of the NDIS and Other Service Systems*, which form part of the Bilateral Agreement between the Commonwealth and Victoria for the transition to the NDIS, Schedule I Management of Interfaces between the NDIS and mainstream services.

In OPA's view and interpretation, the principles are focused on funding demarcations to the detriment of a participant's needs. The principles fail to recognise the complexity of the task. The framework proposed in the principles can in some cases be reductionist and fail to recognise that a clear demarcation of needs serviced by different service systems may not be possible or desirable.

In its submission to this Committee's inquiry on transitional arrangements to the NDIS, OPA presented two areas within the interface of the criminal justice system and the NDIS where the principles create a glaring service gap. This service gap remains. This particular interface continues to be problematic, particularly when it comes to funding ‘offence specific supports’, because disability and offence-related support are inseparable. Supports intervene simultaneously to respond to disability and offence-related areas, each influencing the other. To attempt to separate the two would be an over simplification of human behaviour.

In one of many similar cases, OPA acted as the delegated guardian of an NDIS participant who was placed on a Supervised Treatment Order (STO) under the Victorian Disability Act 2006 and was also an NDIS participant. Disputes are ongoing as to which supports should be funded in the NDIS plan. By way of example, some of the skill deficits that were to be addressed through the STO were supports to develop relationships, develop self-worth, build communication skills, and increase tolerance for coping with distress. Each of these could also be viewed as disability-related supports, but the NDIA declined or reduced funding for supports such as 24/7 core supports as recommended in the STO. In this case, it is difficult to apply the high-level principles to determine the distinct and respective responsibilities of State justice services (offense related) versus NDIS funded services (disability related).

In a past report, the Committee has made the recommendation to “establish an NDIS unit specialising in the interaction of the NDIS with the criminal justice system”. The government response points to an already existing technical advisory team within the NDIA. OPA has yet to interact with this team and despite Victoria now having reached full roll out, the issues at this interface persist, with an increasing number of clients facing repeated hurdles. The NDIA’s technical advisory team does not go far enough to solve these issues and OPA suspects the crux of the issue lies in the principles themselves. OPA considers the principles should be reviewed with the objective of making them applicable to real life circumstances. OPA repeats a recommendation made in its submission to this Committee’s inquiry on transitional arrangements to the NDIS, which is all the more pressing now that the full scheme bilateral agreements have been signed by most States and Territories.

Recommendation 8

The Council of Australian Governments (COAG) Disability Reform Council should review the *Principles to Determine the Responsibilities of the NDIS and Other Service Systems* to ensure they provide clear guidance to resolve interface questions.

5. Participant involvement in planning processes and the efficacy of introducing draft plans

OPA wholeheartedly supports the key principle of the NDIS that all individuals be active agents in decision-making but notes that in practice, the NDIA assumes this to mean that all participants engaging with the NDIS market are free of structural constraints and disadvantages.

The opportunity to have choice and control over one’s disability supports can feel foreign for individuals who have been chronically marginalised and disempowered. Some individuals with disability have been afforded few to no occasions to express their wishes and preferences and, more importantly, have them realised. It can be difficult to imagine ‘what is possible’. OPA finds this to be especially true for individuals who have spent some time in institutions where decisions have continuously been made on their behalf.

Participants with cognitive impairment may require reasonable adjustments in order to fully and meaningfully engage with the scheme and be afforded choice and control. As stated previously, the NDIS Act includes clear provisions to this effect.

The NDIA's *Market Enablement Framework* acknowledges that "participants will take time to fully exercise their power and choice in the marketplace",[21] yet the proposed market levers are, in OPA's view, insufficient. OPA considers the NDIA should extend market intervention activities to better support participants in the planning stage.

The foundation for choice and control, as OPA sees it, lies in shared decision-making between planner and participant. Decision-making is shared when planners meaningfully recognise participants as the experts on their lives and support participants to articulate their goals. While some planners do achieve this, OPA cannot say that this is applied across the board as 'best practice'. This is evidenced by discrepancies in the quality and thoroughness of the plans developed by those participants who are able to self-advocate and/or who have natural supports versus those who cannot/do not.

In this section, OPA identifies strategies that may be required to support participants to exercise choice and control.

5.1. Guide to NDIS decision-making

In its submission to the Committee's 2018 inquiry into market readiness, OPA explored the readiness of NDIS participants to navigate new markets. The submission identified some supports that may be necessary to support individuals with cognitive impairment to engage in the early stages of the NDIS participant pathway, namely at the points of access, pre-planning, and planning.

Following its submission to that inquiry, OPA published the *Guide to NDIS decision-making: When a decision can be made by, with, or for an adult with significant cognitive disability*.[22] The guide outlines when decision-making support, advocacy, and/or substitute decision-making will be needed for potential and current participants at the various stages of the NDIS participant pathway. The publication contains a flowchart that outlines a process to assist in determining the decision-making arrangement that may be appropriate in any given circumstance.

One of the objectives of the guide, which has national application, is to explore the different informal and formal decision-making arrangements that should be considered and provided to participants to enable them to access the scheme, to participate in the planning process, and to receive services in the implementation their plan. The guide seeks to promote informal decision-making supports wherever possible, all the while addressing the complexity around participants with cognitive impairment providing consent to access the scheme.

A draft of the guide was shared with the NDIA for review and feedback and the NDIA expressed no objections to and endorsed the content of the publication.

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[21] National Disability Insurance Agency *National Disability Insurance Scheme Market Enablement Framework* (October 2018) 6.

[22] https://www.publicadvocate.vic.gov.au/our-services/publications-forms/carers/467-guide-to-ndis-decision-making

OPA has widely distributed the *Guide to NDIS decision-making* and has found it to be generally well received by providers and participants, however, the same cannot always be said for NDIA staff. Although the advice articulated in the guide is based on the *National Disability Insurance Scheme Act 2013* (Cth) (NDIS Act) and was endorsed by the NDIA, it is not uncommon for some planners to refute the advice it provides. In practice, OPA has observed a reluctance by the NDIA to promote informal decision-making supports, instead pressing for substitute decision-making arrangements especially in the early stages of a participant's engagement with the scheme.

The NDIS Act gives effect to the UNCRPD in its provisions around the supports that may be necessary for people to make and implement their own decisions. The role of the NDIA is pivotal to facilitate access to these supports. OPA questions whether these legislated objectives are being met at the access and planning stages and in this section, promotes supports that could be called upon to realise these obligations.

5.2. Advocacy

While the NDIA cannot (and should not) represent the wishes and preferences of the participant during the planning process, a planner or LAC can nonetheless assist a participant to obtain any required supports for the planning process, whether formal or informal. Where there is no 'natural' supporter available or where there is conflict in the family, the involvement of an independent advocate should be considered. Referral to an advocate can be made by the NDIA, the planner or LAC, or any another interested person.[23]

The principles of the NDIS Act directly recognise that "the role of advocacy in representing the interests of people with disability should be acknowledged and respected, recognising that advocacy supports people with disability by:

- promoting their independence and social and economic participation; and
- promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and
- maximising independent lifestyles of people with disability and their full inclusion in the community."[24]

Independent disability advocacy can be a useful, sometimes necessary, supplement for some NDIS participants to efficiently navigate the planning process and the NDIS market more broadly. In the transition to the NDIS, however, advocacy organisations faced reductions in funding. Now, OPA is aware that many organisations are struggling and have reported being strained, operating with reduced or uncertain funding, and dealing with increasing waitlists. For participants who rely on advocacy, delays in obtaining an advocate can contribute to delays in planning and poor planning outcomes.

OPA stresses the importance of independent safeguards, such as advocacy, in accessing the NDIS market and realising the intention and the benefits of the scheme for all participants. OPA appreciates and repeats a recommendation previously made by this Committee in its report to the inquiry on transitional arrangements for the NDIS.

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[23] Office of the Public Advocate (Vic) *Guide to NDIS decision-making* (2018).

[24] *National Disability Insurance Scheme Act 2013* (Cth) s4.13.

Recommendation 9

The Council of Australian Governments (COAG) Disability Reform Council should work with the Department of Social Services to address the expected funding shortfalls for advocacy services beyond transition.

5.3. Supported decision-making

Supported decision-making is a central principle of the UNCRPD that has informed much of OPA's advocacy, particularly in relation to proposed guardianship and NDIS reforms. Supported decision-making is premised on the understanding that everybody has the right to make their own decisions and to receive any support they require to do so. The key principles are empowerment, choice, and control.[25]

The commitment of the NDIS to provide people with disability with choice and control is a commendable undertaking and an important shift in the way in which disability services are delivered. One way to embed rights affirming practices within the NDIS planning process is to facilitate supported decision-making. This is not yet part of NDIA processes. As mentioned throughout this submission, OPA has observed an overreliance by the NDIA on substitute decision-making as a means for supporting participants in completing administrative requirements of the NDIS access and planning process (e.g. signing ARF).

In 2018, the National Disability Advocacy Program (NDAP) and the Commonwealth Department of Social Services (DSS) launched the Decision Support Pilot Project. The Decision Support Pilot provides advocacy and decision-making support for potential and current NDIS participants who have limited decision-making capacity and no other appropriate informal (i.e. family, friend, significant other) or formal (i.e. guardian) decision-making supports.[26] In Victoria, the pilot is led by Leadership Plus who have had great success and are now operating at capacity with a wait list.

OPA is encouraged to see funding for the Decision Support Pilot Project extended for another year but continues to advocate for decision making supports to be embedded in standard NDIS processes, starting at the point of access.

Recommendation 10

The Australian Department of Social Services, with States and Territories, should ensure ongoing decision-making supports are available for all NDIS participants starting from the point of access, in line with obligations under the United Nations Convention on the Rights of Persons with Disabilities.

5.4. Plan nominees

The NDIS confers its own substitute decision-making arrangements outside of state-based guardianship laws, under the NDIS Act and further in the *National Disability Insurance Scheme (Nominees) Rules 2013* (Cth) (Nominees Rules).

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[25] Office of the Public Advocate (Vic) *Supported decision making: background and discussion paper.* (November 2009).
[26] http://leadershipplus.com/advocacy/

Under the NDIS Act, a plan nominee can be appointed at the request of the participant or on the initiative of the CEO of the NDIA or their delegate. The CEO or their delegate can appoint a plan nominee. A planner can act as a delegate of the CEO and thus, could effectively appoint a plan nominee.

The Nominees Rules provide that a plan nominee can undertake actions on behalf of a participant in relation to the preparation, review, or replacement of the participant's plan, or the management of funding for supports under the participant's plan.[27] These acts may be done by the plan nominee to the extent specified in the instrument of appointment, noting that the CEO or delegate can limit the matters that a plan nominee is appointed to deal with.

In 2014, OPA published the *Guardianship and the NDIS: Discussion paper*[28] to explore aspects of the interface between the appointment and scope of the roles of a guardian and plan nominee. The paper is still relevant and OPA repeats some of its key considerations here.

How is a plan nominee appointed?

The Nominees Rules state that the appointment of a plan nominee is justified only when it is not possible for the participant to be assisted to make decisions for themselves.[29] The NDIA has developed an operational guideline to assist planners and other NDIA staff acting as delegates of the CEO to determine whether the appointment of a nominee is necessary. General considerations include that the CEO (or delegate) have regard to the participant's wishes (including the existence of formal and informal networks around the participant). Presumably, if other formal or informal arrangements are operating effectively, the CEO or delegate will not find it necessary or justifiable to appoint a plan nominee,[30] yet OPA finds this to not always be the case.

The appointment of a plan nominee can be a restrictive action. It can result in a participant's right to make a decision being unduly restricted or even removed, for example if the appointed nominee decides that the participant is not capable of doing an act or thing. Yet procedural safeguards built into guardianship legislation are not reflected in the NDIS Act to oversee the potential restrictions on a participant's rights.

The Nominee Rules state that '[p]eople with disability are presumed to have capacity to make decisions that affect their own lives', and that that 'appointments of nominees will be justified only when it is not possible for participants to be assisted to make decisions for themselves'.[31] There is no guide to the applicable test or principles to be applied when undertaking that assessment.

In Victoria, VCAT has the sole power to appoint guardians only if they are satisfied that the person has a disability, cannot make reasonable personal and lifestyle decisions because of that disability, and needs a decision made for them or about them and there are no

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[27] *National Disability Insurance Scheme (Nominees) Rules* (Cth) s3.7

[28] https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/ndis/decision-making/329-guardianship-and-the-ndis-discussion-paper-2014-1

[29] *National Disability Insurance Scheme (Nominees) Rules* (Cth) s2.1.

[30] Office of the Public Advocate (Vic). *Guardianship and the National Disability Insurance Scheme: Discussion Paper*. (September 2014).

[31] *National Disability Insurance Scheme (Nominees) Rules* (Cth) s3.1 & 3.3

alternative, less restrictive methods of making the decision.[32] It is unclear whether similar considerations are involved in the appointment of plan nominees.

VCAT holds primary responsibility for overseeing the activities of substitute decision makers through regular reassessments of their appointments, among other things. OPA is not aware of an equivalent body who could perform this role in the Commonwealth sphere. It is OPA's understanding that there are no legislative provisions authorising the NDIS Quality and Safeguards Commission (or any other body) to accept complaints against plan nominees nor to proactively monitor plan nominee appointments.

OPA continues to advocate for a more robust framework of safeguards and accountability mechanisms, proportionate to the restrictions that such an appointment could impose on a participant, to be included in the NDIS Act in relation to the appointment of plan nominees.

Should guardians be appointed as nominees?

A guardian with relevant authority (i.e. access to services and/or accommodation) can represent the wishes and preferences of the participant in the planning discussion. Guardianship laws in each state and territory generally require a guardian, when making a decision, to act as an advocate for the person, to act in consultation with the person, and to take their wishes into account.

Where a participant has a guardian with relevant authority, the NDIA can choose to appoint the guardian as a participant's plan nominee. To this point, the NDIA policy position is that "where it has been identified by the NDIA that the participant requires a nominee and there is a guardianship arrangement in place, the presumption is that the guardian will be appointed as the nominee."[33] Further, "there is a presumption that a guardian should be appointed nominee where their responsibilities are comparable to the duties of a nominee".[34] OPA contests these presumptions.

The presumption that a guardian will have comparable duties to a plan nominee is illustrative of some of the misconceptions about the proper limitations on a guardian's role. The powers attributed to a plan nominee are usually much broader than those accorded to a guardian. For instance, a plan nominee can act on behalf of a participant to manage funding for supports under their NDIS plans, whereas a guardian would arguably (at least in Victoria) never have the authority to direct a represented person's finances. OPA appreciates that the NDIA could restrict the nominee appointment to only include some actions and thus align the appointment with the authority of a guardian, but OPA has not seen this occur. Consequently, as a general rule, OPA refuses the appointment as a plan nominee to avoid confusion. In any case, a guardian with relevant authority would not require an appointment as plan nominee to carry out their legislative functions.

When there is a guardian and a plan nominee

The Nominees Rules prescribe 'requirements with which the CEO is to comply when appointing a nominee'. The Rules state "the CEO is to consult, in writing, with any court-appointed decision-maker or participant-appointed decision-maker in relation to any

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[32] *Guardianship and Administration Act 1986* (Vic).

[33] https://www.ndis.gov.au/understanding/families-and-carers/guardians-and-nominees-explained

[34] Idem.

appointment".[35] In OPA's experience, these legislative requirements are not consistently applied. For example, in one instance, an OPA delegated guardian was informed that they had, unbeknownst to them, been appointed as plan nominee by the participant's planner.

In the rare instances where the Public Advocate is appointed as guardian for a participant for whom a plan nominee arrangement is already in place, there has been miscommunication and tension between the roles. Having both a guardian with relevant authority (access to services and/or accommodation) and a plan nominee creates an overlap in substitute decision-making authority that can be difficult to manage.

The interaction between the two roles – guardian and plan nominee – is complex. While the legislation provides clarity about the interface between the roles, it is OPA's experience that not all planners or nominees necessarily understand the respective roles. In one case, the Public Advocate was appointed guardian for an NDIS participant whose sister was plan nominee. The sister had in fact applied to VCAT to be appointed as guardian but VCAT declined to appoint her to the role because of conflict within the family. The sister was difficult to reach, not only by the guardian but also by the NDIS planner and service providers who required her involvement in order to plan and contract services for the participant. The NDIS planner, in good faith, requested that the delegated guardian sign off on NDIS related decisions to expedite the process for the participant, seemingly not understanding the boundaries in decision-making authority between the plan nominee and the delegated guardian. According to OPA's interpretation of legislation, the nominee should overrule the guardian on any decision that relates to the NDIS plan. This effectively means that while a guardian can (and should) be consulted and can continue to advocate on behalf of the participant, they cannot effectively make any NDIS related decisions on behalf of a participant, as this responsibility falls to the plan nominee.

Where both a guardian and a plan nominee have been appointed and no decisions need to be made that lay outside of NDIS funded services (and therefore under the guardian's authority), the guardianship appointment would in effect be redundant.

Are nominees substitute or supported decision makers?

OPA supports the option for participants to request a plan nominee. A plan nominee has substitute decision-making capability, but the intention of the role seems primarily to be to support to the participant, consult with them, and manage the participant's plan. Ultimately, "a plan nominee appointed on the initiative of the CEO is able to do an act on behalf of the participant only if the nominee considers that the participant is not capable of doing the act."[36] In practice, this means that a nominee could act both as a supported or a substitute decision maker, depending on the decision at hand. OPA questions whether grouping the two roles under the same appointment is appropriate. In Victoria, legislation such as the *Powers of Attorney Act 2014* and the new *Guardianship and Administration Act 2019* clearly separate the roles of substitute and supported decision maker.

The establishment of distinct appointments for supported and substitute decision-makers enables appropriate and distinct oversight of the two roles, ensuring the appropriate use of substitute decision making. OPA stresses that supported decision-making should remain the preferred and less restrictive option to substitute decision-making and should be

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[35] *National Disability Insurance Scheme (Nominees) Rules* (Cth) s4.12.

[36] *National Disability Insurance Scheme (Nominees) Rules* (Cth).

promoted, facilitated, and utilised by planners and participants wherever possible. To blend the role with substitute decision making under one appointment can cloud the responsibilities of a plan nominee who is afforded the ability to move from one role to the other with little to no oversight. Without appropriate clarity and safeguards around substitute decision-making for plan nominees, there is potential for unnecessary restrictions to be placed on a participant's decision-making authority.

Recommendation 11

The Australian Government should amend the *National Disability Insurance Scheme (Nominees) Rules 2013* to include more robust safeguards in relation to nominees, akin and aligned to state and territory guardianship legislation.

5.5. Pre planning

To articulate goals and aspirations and identify the supports necessary to achieve them in a single meeting can be challenging. A single meeting does not provide participants with the opportunity to understand and collect, for example, all the necessary assessments and documentation that will be required to support their claims. Pre-planning should form an integrated and distinctive step in the planning process to provide all participants with an opportunity for participants to view a draft plan and workshop the supports that may be required to achieve their goals.

OPA and Community Visitors observe that preparation for planning is a critical step in the process. Seemingly simple things, such as grasping the terminology of the scheme can make a noticeable difference in the quality of the plan.

OPA supports a recommendation made by the Committee in its report on the inquiry into transitional arrangements for the NDIS that the NDIA should ensure that people with disability can access pre-planning supports and stresses the urgency of its implementation.

In its response, the Australian Government pointed to two initiatives: a new participant pathway and a pre-planning resource. In its submission to this Committee's inquiry into market readiness, OPA commented that few opportunities are afforded to participants to meet with a planner on more than one occasion. OPA and Community Visitors observe that this continues to be the standard way of operating, outside of the Complex Support Needs Pathway, despite the Committee's recommendation.

OPA is not aware of pre-planning occurring with a LAC, as intended in the new pathway that was alluded to in the government's response. However, OPA has observed the terminology of 'pre-planning' being used in a misleading way. Participants and their guardians have sometimes been invited to 'pre-planning' meetings only to realise after the fact that the pre-planning meeting was to be the only meeting that would take place.

The pre-planning resource is available on the NDIA's website but remains a 'light touch' intervention that does little to proactively prepare participants or to recognise the iterative nature of the planning process. Furthermore, the information is not necessarily presented in a format that is accessible to participants with cognitive impairment.

Again, additional strategies should be put in place to support participants in the planning stage, in different ways. The Committee's recommendation unfortunately remains relevant.

Recommendation 12

The National Disability Insurance Agency should ensure that across all jurisdictions people with disability can access pre-planning supports.

5.6. Draft plans

OPA and Community Visitors report that participants are not usually privy to a draft plan. OPA acknowledges the NDIA's move towards joint planning meetings but is surprised to see that the roll out of this new process is contingent upon a "detailed evaluation of the soft launch"[37] of the pilot. If the NDIS is to genuinely give participants choice and control, all participants should be afforded the opportunity to view a draft plan.

Recommendation 13

The National Disability Insurance Agency should review its planning process to ensure that all participants can view a draft plan.

Community Visitors have visited participants who do not have a final NDIS plan (but are receiving NDIS supports) or who have not received a plan in a format that is accessible to them (i.e. in plain or Easy English). The NDIA points to recent improvements made to the formatting of their plan, but OPA considers more can be down to make plans more accessible, especially for participants with cognitive impairment. OPA repeats a recommendation made in *The Illusion of Choice and Control* for suggested formatting of NDIS plans.

Recommendation 14

The National Disability Insurance Agency should provide clear breakdowns and descriptions of the specific supports to be provided under each line item in participant plans. Where the amount of funding is significant, more detailed breakdowns should be provided.

6. Reassessment and review process

One of the successful features of the Complex Needs Support Pathway is its built-in flexibility whereby funding can be adjusted according to a change in circumstances without necessitating a reassessment or plan review. OPA believes that some form of expedited process for reassessments and reviews could be beneficial for all participants, not only those in the Complex Support Needs Pathway, who may require adjustments to their NDIS funding to respond quickly in the event of an 'urgent change in circumstances'.

In the example provided above of the NDIS participant who was banned from taking a shared mode of transport due to behaviours of concern, the NDIA was unable to respond to a rapidly changing need for additional transport funding. Without supplementary funding, the participant lacked funds to afford individual transport to the day program, an essential activity, through his NDIS plan.

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[37] National Disability Insurance Agency *Submission to the Joint Standing Committee on the NDIS Inquiry on planning* (2019) 6.

OPA repeats a recommendation made in its report *The Illusion of Choice and Control.*

Recommendation 15

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

6.1. Specialist Disability Accommodation (SDA) reassessments

OPA and Community Visitors have received advice that an SDA relocation, whether initiated by a participant or other interested party, necessarily requires a reassessment. The intention of a reassessment in this circumstance is, presumably, to provide a participant with choice and control over the features of the next SDA however, there are delays in obtaining reassessment that can have adverse effects on participants, for example by maintaining a participant in an unfavourable or unsafe accommodation setting.

In one example, Community Visitors advocated on behalf of a participant living in an SDA who was subject to abuse by a co-resident. The participant requested a relocation, which, for obvious safety reasons, needed to occur quickly. Delays in obtaining a reassessment left this person with no other option than to wait in their current environment. The perpetrator of the abuse would have presumably faced similar delays had they been asked to relocate.

One possible remedy to situations like this is to include Short Term Accommodation and Assistance (STAA) funding in a person’s plan to facilitate access to safe accommodation or respite in the event of a crisis that threatens safety or wellbeing. In their 2017-18 Annual Report, Community Visitors reported low levels of funding for STAA, specifically for respite, in NDIS plans, causing families to be “reluctant to use respite until absolutely necessary, which has led to underutilisation of these services in some areas.”[38] The reasons for limited STAA funding in participant plans are unclear to Community Visitors. Participants without STAA funding who have the financial resources may choose to access and fund an STAA provider out of pocket in order to access respite services on short notice. This is inequitable.

Service providers are also impacted by the shortage of STAA funding in NDIS plans. For example, one STAA provider accepted participants who did not have STAA funding in their plan because the participants needed urgent support. The need for STAA can occur for a variety of reasons (e.g. due to ageing or a primary carer no longer being able to fulfil this role) but is often in response to a sudden change in circumstance. The STAA service provider in this case advised Community Visitors that they have carried a backlog of outstanding payments from the NDIA, for many months and in one case, for over one year. Increasingly, STAA providers are advising Community Visitors that the STAA is not financially viable under the NDIS funding model. This is an alarming development when STAA are relied upon as a critical safety net to support participants awaiting an SDA relocation assessment.

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[38] Community Visitors *Annual Report.* (2017-18) 8.

The impact of SDA and STAA market development issues on participants is real and concerning. Market intervention is necessary and pressing. OPA raised this in its submission to the NDIS Thin Markets Project and in its 2018 report *The Illusion of Choice and Control,* which presents the stories of eleven NDIS participants, some of whom are impacted by shortages in SDA and STAA. For many, the absence of NDIS funded accommodation keeps them in situations of unnecessary detention, in the health, mental health or criminal justice system, at great cost and impact to these systems. Some are thrust into situations of homelessness, while others, as in the case above, remain in situations of abuse.

The issues related to accessing or relocating from SDA or STAA are multi-faceted and it would be simplistic to attribute them squarely to the NDIS planning process. Indeed, the solutions must be framed within a broader discussion around thin markets, providers of last resort, and residential safeguards. OPA has explored these issues and made recommendations in reports and submissions to previous government inquiries, and while market intervention is required, there remains a need for the SDA reassessment process to respond swiftly if it is to maintain or improve outcomes for participants, especially those who are subject to abuse or a notice to vacate.

OPA speaks more to this issue in its submission to the Committee’s concurrent inquiry into SIL. OPA repeats here a recommendation made in that submission.

6.2. Review process

It is unclear whether there is a process in place to automatically and systematically trigger plan reviews. Community Visitors often see residents in disability services whose plans have expired but they are unsure whether they need to request a review, or by which process the review will occur. OPA delegated guardians are sometimes informed that an NDIS plan review has occurred for a participant without their knowledge. In some instances, participants themselves were not made aware that a plan review was scheduled. This raises questions as to the NDIA’s method for engagement with participants and whether information for reviews is being provided in the best or most accessible format.

OPA has further concerns around how decisions are made during plan reviews, particularly in relation to low utilisation of certain services. In many cases, participants are unable to fully utilise allocated funding due to market development issues such as thin markets. Most notable are shortages of support coordinators, which can halt spending on all other services in a plan. Community Visitors have remarked that some participants have seen substantial reductions in their funding as a result of underutilisation, despite having a need for certain services. Planners should consistently question participants to identify any underlying market development issues and take this into consideration. The NDIA should, as market steward, make use of this data to inform its market intervention activities.

7. Circumstances in which longer plans could be introduced

The evidence provided in this submission demonstrates the immense administrative effort that is required of participants at the stages of access and planning. For any participant, including those who have limited supports and/or cognitive impairment, the bureaucracy of the planning process can lead to fatigue, be disempowering, and, in the worst of cases, can contribute to negative outcomes.

The one-year life span of NDIS plans has flow on consequences. From the viewpoint of the NDIA, it may be an unsustainable schedule for staff to maintain. For participants, planning on a yearly basis brings additional paper work. For example, with every new plan, participants must renew and sign service agreements for each funded service. OPA recently published *NDIS Service Agreements: Making Choice and Control More Real* which speaks to the challenges faced by participants with complex and challenging support needs in negotiating and signing NDIS service agreements.

OPA considers that a one-year plan life cycle may be appropriate for a participant’s first plan, but consideration should be given to making longer plans (e.g. three years) in appropriate circumstances. The choice should ultimately be given to the participant and should a longer plan be preferred, participants should have the ability to seek an expedited review if their needs change significantly.

OPA acknowledges the NDIA’s current work on issuing guidance to planners and LACs regarding two to three-year plans. Similar to the NDIA, OPA hopes the review of the NDIS Act will inform this guidance.

8. Plan implementation

8.1. Support coordination

Following receipt of their plan, a participant must then implement supports by choosing their preferred providers within the NDIS market. The support coordinator, if and where appointed, aids in choosing and coordinating providers, developing service agreements, and managing the funding in an NDIS plan. At the time of a plan review, support coordinators are well placed to comment on the quality or effectiveness of services. Thus, support coordinators support participants in exercising choice and control.

A support coordinator cannot choose providers, nor can they sign service agreements on behalf of the participant. They can however accompany a participant in making these decisions. As such, support coordination is certainly necessary, but does not adequately address more generalised decision support that many isolated individuals with cognitive impairment require to engage with the NDIS and their NDIS-funded supports.

Furthermore, because of their influential role in the implementation of NDIS plans, support coordinators can face an obvious conflict of interest if they are employed by an organisation that is providing other NDIS funded services under the same plan. To receive multiple services from a single provider may be beneficial to some participants, for instance, in rural areas where the market may be scarce. However, it does also have the potential to become problematic for participants who may not have the capacity to fully understand the implications of this ‘double appointment’.

OPA speaks to the potential dangers of engaging a support coordinator from the same provider as SIL in its submission to the Committee’s concurrent inquiry on SIL and repeats a recommendation made in that concurrent submission.

Recommendation 16

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.

As previously mentioned, OPA is glad to see the support coordinator workforce grow and develop but still identifies a thin market in the availability of support coordinators who are willing and appropriately skilled to work with participants with complex needs.