

Northern Territory Public Guardian and Trustee Submission to the Joint Standing Committee on the National Disability Insurance Scheme

CAPABILITY AND CULTURE OF THE NDIA INQUIRY

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Introduction

The Northern Territory Public Guardian and Trustee (PGT) welcomes the opportunity to provide a submission to the Joint Standing Committee's inquiry into the Capability and Culture of the National Disability Insurance Agency (NDIA). The National Disability Insurance Scheme (NDIS) has enhanced the lives of many people with disability in the Northern Territory and PGT looks forward to our continued work with the NDIA. The Committee's inquiry and the PGT's submission is an opportunity to reflect on how the NDIA's current processes and procedures can be developed to improve the experiences and outcomes for people with disability and participants.

The PGT is a newly created administrative entity formed through the amalgamation of the Northern Territory Office of the Public Guardian and the Public Trustee for the Northern Territory. The amalgamation is the result of Ms Beth Walkers' dual appointment as Public Guardian and Public Trustee and strengthens the PGT's capacity to advocate for adults with impaired decision-making capacity across all spheres of the guardianship and disability space.

The PGT provides guardianship, financial management, estate administration and will services to the Northern Territory community in accordance with relevant legislative functions including those outlined in section 61 of the *Guardianship of Adults Act 2016*, which pertain to the functions of the Public Guardian. Included in these are the core functions of advocacy, promotion of access to services and encouragement of service providers to monitor and review the services they provide.

The PGT is responsible for personal and lifestyle decision-making for approximately 670 adults, 77 per cent of which identify as Aboriginal¹, across all regions of the Northern Territory. With around 95 per cent of these represented persons² being current NDIS participants, the PGT has attended nearly all initial and review planning meetings for these participants in addition to the initial and review planning meetings of past participants. This involvement has provided considerable insight into the experiences of participants with impaired decision making capacity³ when navigating the complexities of the NDIS.

The Northern Territory context

The unique geographic and social environment has impacted the implementation of the NDIS

¹ The term Aboriginal is used in this document to refer to all people of Aboriginal and Torres Strait Islander descent who are living in the Northern Territory. The use of this term reflects the wishes of Aboriginal people in the Northern Territory. Department of the Attorney-General and Justice (2019). *Northern Territory Aboriginal Justice Agreement 2021-2027*.

² For the purpose of this submission represented person means a person who is under a guardianship order and the Public Guardian is appointed with decision-making authority for this person.

³ As guardianship orders come into effect when a person reaches the age of 18, all experiences of the Public Guardian and Trustee in relation to the NDIS is with participants over the age of 18.

across the Northern Territory. The challenges experienced in scheme implementation and forecasting in other jurisdictions are exacerbated in the Northern Territory. The combination of harsh climates and rough terrain means health and other supports and services in many parts of the Territory are limited. The Northern Territory's transient population impacts the retention of the skilled workforce as capable individuals have many alternate options elsewhere in Australia and the high cost of living is an additional challenge for those in the low socio-economic circumstances. These complex challenges demand innovative and tailored solutions to meet the needs of Territorians with disability.

While most Territorians live in regional centres, a significant number live in remote and very remote areas. For Aboriginal people, who make up 30 percent of the Northern Territory population⁴, almost 77 percent live in remote or very remote areas⁵, resulting in a small population spread across vast distances posing significant challenges to private and government service delivery.

The PGT continues to observe a high level of represented persons that identify as Aboriginal experiencing significant difficulties in receiving appropriate support services, including health care and NDIS supports and services in remote communities necessitating a relocation to regional centres resulting in a disconnect from country and culture, which is an essential element of Aboriginal life.

PGT's engagement with Committee inquiries

The former Office of the Public Guardian has made submissions to the Committee between 2017-2022 in relation to transitional arrangements, market readiness, NDIS planning, supported independent living, the NDIS workforce, the NDIS Quality and Safeguards Commission, independent assessments and the NDIS scheme implementation and forecasting.

Submissions of PGT in relation to:

- ***the capability and culture of the NDIA, with reference to operational processes and procedures, and nature of staff employment and***
- ***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***

The capability and culture of the NDIA, with reference to operational processes and procedures can be described as complex, bureaucratic and inflexible, with a participant's experience being dependent upon the expertise and skills of individual staff rather than the processes and procedures of the Agency. The capability and culture of the NDIA is not reflective of a scheme in which the participant is at the heart of all processes and procedures or in which the participant's choice and control is paramount.

⁴ Department of Treasury and Finance (NT), Population - Northern Territory Economy: Aboriginal Population (2022) [Population - Northern Territory Economy](#)

⁵ Ibid

Despite initiatives by the NDIA to improve participants' experiences such as the implementation of the Participant Service Charter and the Participant Service Guarantee there has not been widespread change to the capability and culture of the Agency. This is evidenced by many of the issues raised in previous submissions to the Committee still being relevant and addressed in this submission.

Support for decision making

In the absence of a support for decision making framework within the NDIS, the PGT has observed a growing trend for persons with impaired decision-making capacity to have a formal guardian appointed to enable them to navigate the scheme. This is in conflict with a scheme in which independence, choice and control and the participant's human rights are central objectives.

Support for decision-making and participant skills development has significant potential to address this trend and reduce the need for the appointment of a guardian for participants who may have capacity to make supported decisions. This potential was addressed in the PGT's submission to the NDIA Support for Decision Making consultation, which sought responses to a proposed new Support for Decision Making policy outlined in their *Consultation paper: Supporting you to make your own decisions*.

The PGT understands that following consultation, the NDIA employed a co-design process to develop the final Support for Decision Making policy which is expected to be implemented in early 2023. While this is a welcome initiative by the NDIA the PGT advocates for a supported decision making framework to be formalised in the NDIS legislation. The framework must then be embedded across the NDIA and the whole NDIS through comprehensive training and skill development of participants, NDIA staff, NDIS service providers, families and guardians.

Additionally, NDIS plans should contain funding to enable the participant to develop their skills in the area of supported decision making, self-advocacy and financial literacy. This would enable participants to exercise choice and control to the greatest possible extent in connection with their NDIS plans, and to exercise their individual autonomy more broadly. It will also reduce reliance on the guardianship system to assist participants to navigate the NDIS.

Decision making within the NDIA

The PGT experience of the NDIA is that it is bureaucratic with decision making delegations at a high level and NDIA decision makers not directly engaged with participants and their individual circumstances, including the unique context of their community. This means:

- it is not possible for participants, their families and decision makers to engage in an open dialogue about participant needs, reports or the reasons for decisions with the NDIA decision maker with authority to approve the participant's plan (and associated supports and funding)

- information on behalf of or about a participant is filtered through various levels of NDIA staff before it is considered by the person with the required delegation to make a decision in relation to it
- it is more likely that the NDIA decision maker will not have an understanding of the participant's community and its unique context including different facilities and service provision landscape.

When the NDIA decision maker is not directly engaged with the participant there is an increased risk that the supports and needs of the participant will not be appropriately understood, that the proposed services and supports may not be deliverable in the participant's community and that the participant's plan may not meet their desired outcomes. It also makes the NDIA process slow, unresponsive and lacking in the agility to respond to an individual's changing needs and circumstances. This can place participants in vulnerable situations with support needs not being met.

With the involvement of local area coordinators (who are not NDIA staff) the above risks are amplified as information is shared across different organisations in order for a NDIA planner to approve the participant's plan.

Knowledge and expertise of NDIA staff

A participant's experience is dependent upon individual staff within the NDIA and the staff member's knowledge of disability, their understanding of the participant and their commitment to a NDIS plan that meets the goals of the participant. However, the knowledge and expertise of NDIA planners and other staff is variable with some NDIA staff having limited understanding of different disabilities and the rights of people with disability. This results in inconsistent plan funding between participants and also plan gaps in which required supports (and at an appropriate level) for a participant are not funded.

Issues also arise when the planner is not familiar with the service profiles of different locations in the Northern Territory, as there are significant differences in the services available at Alice Springs, Tennant Creek, Katherine and Darwin or in remote communities.

Preparedness for plan meetings is also an essential element of successful plan development. Although relevant and up to date reports are supplied to NDIA staff (and local area coordinators) prior to plan meetings, often the NDIA staff will not have read the documents prior to the meeting or do not understand the significance of the information within the documents.

The characteristics of the Complex Support Needs Pathway creates a capability and culture that should be replicated across the whole of the NDIA. It is characterised by qualified and experienced NDIA staff with advanced understanding of different disabilities and an increased agility to respond to a participants' needs and undertake desktop reviews and approve supports in a considered but

timely manner. The effect is often positive experiences and outcomes for NDIA participants, their families and decision makers.

Relationships with individual NDIA staff

At different times staff of the PGT have been able to build relationships with NDIA managers and have had the opportunity to discuss plan and funding concerns on behalf of participants involved with the PGT. When these relationships are strong and NDIA managers are open to creative thinking and solutions these discussions are more likely to result in improved outcomes for participants. A simple example is a NDIA manager reviewing a funding decision informally (where there may have been an error or misunderstanding on the NDIA's part) instead of requiring the PGT to lodge a formal request for a section 100 internal review.

When the PGT do not have a single point of contact or an established relationship with a particular NDIA team the experience of PGT is that the team is less responsive to PGT's concerns or queries and more bureaucratic in their response. This might include by not considering informal or creative solutions and instead relying upon the burdensome processes and procedures of the NDIA, for example the lodgement of a section 100 review for all occasions that a query is raised in relation to a reviewable decision.

The NDIA workforce

The implementation of initiatives by the NDIA to change the existing capability and culture is challenged by staff turnover. In particular the PGT is aware that it has been particularly challenging to recruit to NDIA positions in Alice Springs due to high living costs and social issues currently being experienced within the town. This is a similar challenge being experienced by many service sectors. Often multiple services and agencies are recruiting from the same small workforce pool due to unsuccessful attempts to attract interstate applicants.

Inadequate staffing levels and frequent turnover of staff exacerbate the difficulties previously addressed in this submission when NDIA staff are not directly engaged with the participant, do not understand the participant and their circumstances and/or do not have a relationship with participants, their families and decision makers.

Reductions in SIL funding

The PGT has observed a trend of the NDIA reducing SIL funding when plans are reviewed. Sometimes the decision might be to reduce SIL funding gradually to facilitate a step-down in supports over a very short period or it might be cut substantially without any step-down process. On other occasions some Aboriginal participants living in remote and very remote communities who require SIL and apply for it are having their applications rejected outright. Reductions of SIL funding often occur in circumstances where there have been no relevant changes in the participant's situation or disability, or where the relevant evidence and reports support the SIL funding being increased or maintained at the current level. In many instances there is no discussion

or consultation about these changes (including at planning meetings) and they are not identified until the relevant plan is received.

Despite the NDIA's decisions to reduce SIL funding often being in contradiction to the relevant evidence and reports the NDIA does not routinely question the content or value of a report and they do not seek clarification about the points of concern from the author or other stakeholders (including the PGT) until after a decision has been made and is subsequently being challenged.

The decision to reduce SIL funding appears to occur without an appreciation by the NDIA of the Northern Territory context and the lack of alternative models of accommodation options. Alternative models to SIL, including the Individualised Living Option (ILO) are challenged in the Northern Territory because there is a fundamental lack of options in the housing and supported accommodation market. Two key barriers include the high demand for affordable housing and there are very few organisations currently willing and able to provide services to a participant within the ILO model. These barriers are exacerbated in remote and very remote communities.

The development of alternative accommodation types in the Northern Territory would allow more participants currently living within SIL services to safely transition to more independent settings. This would enable participants to develop their skills and independence in a safe way. As the funder of the scheme, and steward of the disability services market, the NDIA should play a role in market development, including exploring and solving problems with the market. The NDIA is well positioned to advise State and Territory governments (who have responsibility for housing policy) about the high level of demand for this intermediate model of housing.

Other funding reductions, plan changes and adjustments

The PGT has also observed funding reductions in some participants' plans for other supports including medication assistance, diabetes assistance, occupational therapy, speech therapy, behaviour support plans and support coordination. These reductions have occurred without NDIA decision makers having a real appreciation of support needs of the participant and the effect that the funding reductions will have on them, including their physical and mental health or wellbeing.

The PGT has witnessed plan changes and adjustments occur without sufficient consultation with the participant and their support coordinator. This has meant there is no or insufficient time to facilitate a smooth transition to new service arrangements causing distress and disruption to the participant and also their support coordinator and services providers as they are required to rapidly adjust to the changes.

Review of NDIA decisions

Dissatisfaction with NDIS plans and the outcome of internal review processes has resulted in an increase in applications to the Administrative Appeals Tribunal (AAT). It is the experience of the PGT that internal reviews frequently result in confirmation of the original decision but the reasons for this confirmation are often general and opaque, only quoting the relevant legislation and

asserting that the supports sought are not reasonable and necessary without explaining how the decision maker used the reports and evidence to reach their decision. An appeal to the AAT is then necessary to further explore the decision making processes of the NDIA in an attempt to obtain a more positive outcome for the participant.

The increase in applications to the AAT is evidenced by the fact that in early 2022 the Northern Territory Legal Aid Commission was forced to cease providing legal representation for participants making appeals to the AAT due to the exhaustion of their NDIS legal service funding. This resulted in Territorians having no avenue to appeal plan funding decisions made by the NDIA as there was no other organisation providing this service in the Northern Territory.

Pursuing an appeal in the AAT is costly and time consuming. For participants involved with the PGT it has meant the PGT has been required to engage in both informal and formal advocacy on behalf of these participants where there are issues with their NDIS plans such as funding cuts. This is time and resource intensive for officers within PGT and the level and strength of advocacy needed illustrates the significant disadvantage of NDIS participants who do not have access to an advocate or legal representation.

The experience of Aboriginal participants

In public hearing 25 the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability received significant evidence about the experiences of Aboriginal people living with disability in remote and very remote communities with the NDIS. This evidence included how the NDIA capability and culture impacts these experiences. Ms Beth Walker, the Northern Territory Public Guardian and Public Trustee gave evidence at this hearing and provided insight into the experiences of Aboriginal participants involved with the Public Guardian and Public Trustee and how these experiences are impacted when the participant lives in a remote or very remote area.

The processes and procedures of the NDIA and the cultural competence and safety of NDIA staff create barriers for Aboriginal people with disability to access and fully engage in the NDIS in the following ways:-

- Aboriginal participants are unable to stay on country in remote and very remote communities because the services they need are not present in these places including SIL services and specialist disability accommodation.
- The grief associated with an Aboriginal person's disconnection from culture, kin and community may result in sub-optimal engagement by the participant in their new environment and services and the development of new or exacerbation of existing behaviour or mental health issues.
- The NDIA's reliance on documentary evidence means that Aboriginal participants are often required to seek expert reports from practitioners who are not familiar with them and are not based in their community. These practitioners may be inexperienced in working with Aboriginal people and might provide culturally unsafe care. The participant might need to

travel large distances to obtain these reports. The need to repeat this process to obtain the numerous reports required by the NDIA compounds the risk of culturally unsafe care, and increases disruption to the participant.

- Return to country trips are not currently considered a reasonable and necessary support and the NDIA do not attach the appropriate importance to them. The PGT has observed funding for return to country trips is increasingly being denied or reduced. Return to country trips are important to enable Aboriginal participants to maintain their connection with country, culture and community and are central to emotional and physical wellbeing. A denial or reduction in return to country trips increases a participant's disconnection from country, culture and community and can result in decreased engagement with the participant in services and supports because their social, emotional and spiritual needs are not being met.
- The limited and/or sporadic cultural competence of NDIA personnel means interactions with Aboriginal participants may not be culturally safe and there may be an inadequate appreciation of cultural norms and nuances including through language.

The PGT often engages cultural consultants and advisors to act as an intermediary with Aboriginal participants for a number of purposes in connection with the NDIS, including to assist participants to understand the functions of the NDIS, to better understand the participant's wants and needs in relation to services and supports and to assist with the planning and coordination of successful return to country trips. The use of a cultural consultant and advisor ensures that a participant's experience of the NDIS is culturally safe, optimising the participant's engagement with the NDIS and the outcomes they are able to achieve. For these reasons, Aboriginal participants should be entitled to receive funding for cultural consultants and advisors within their NDIS plans.

Return to country trips should also be appropriately funded in participant's plans. Creativity, flexibility, planning and close engagement with an Aboriginal participant is required to determine what sort of return to country support is needed and how it can be achieved. NDIA staff should consider if the person seeking to maintain their connection to country, culture and community or to explore or increase their connection and also if the participant has any specific cultural obligations in relation to traditional occasions.

Support co-ordination funding

The Public Guardian and Public Trustee are guardians of last resort. They are appointed for decision making purposes and do not provide case management functions. The role and functions of guardians of last resort are not well understood within the NDIA resulting in impracticable expectations of what can be achieved by the guardian.

The appointment of a guardian of last resort should provide an indication to the NDIA that the participant is likely to require support coordination funding. There must also be an acknowledgement by the NDIA of what can reasonably be achieved within funded hours and an understanding of the role and limitations of a guardian of last resort. Inadequate support

coordination funding can increase the risk of a participant not receiving funded supports and not having their support needs met.

Inability to access the NDIS Portal

The NDIS Portal is linked to each participant's MyGov account (and consequently all of the other government services linked to that account). Although the PGT is legally entitled to access a represented person's NDIS Portal, while it is linked to their MyGov account there are privacy and technical issues associated with this access. Systems changes should be made to the NDIS Portal to enable guardians and trustees to access this portal on behalf of participants without this access including access to all other government services linked to the participant's MyGov account.

Access to the NDIS Portal for guardians and trustees would allow the PGT to better fulfil its statutory function of looking after the interests of participants involved with the PGT, without relying on support coordinators to attain current and detailed information about what spending has occurred under a participant's plan.

Conclusion and recommendations

There is a direct and indisputable link between the NDIA capability and culture and the experiences of people with disability and NDIS participants trying to access information, support and services from the Agency. Despite positive outcomes for many participants the NDIA capability and culture (complex, bureaucratic, inflexible) generally means the experiences of participants with the NDIA is not optimal. Positive experiences are often attributable to individual NDIA staff and teams and the sub culture that they have created.

The PGT makes the following recommendations to develop the capability and culture of the NDIA and improve the experiences of people with disability and NDIS participants trying to access information, support and services from the Agency:-

- The NDIA legislate a support for decision making framework in the NDIS legislation. The framework must then be embedded across the NDIA and the whole NDIS through comprehensive training and skill development of participants, NDIA staff, NDIS service providers, families and guardians.
- The NDIA adopt a more decentralised decision making model. Within this model, NDIA decision makers should engage directly with participants, their families and decision makers to ensure that decisions properly account for individual participants' needs and local variations between different remote and very remote areas.
- Staff within the NDIA should receive initial and ongoing training in relation to different types of disability, the experiences of people with disability, the cultural safety of Aboriginal people with disability and how decision making, processes and procedures within the NDIA can uphold the human rights of people with disability. Skill development should also occur in relation to communication techniques and building stronger relationships with participants, their families and decision makers.

- Reductions in SIL funding or other plan funding should be discussed with the participant and should only occur when the participant has sufficient time to adjust the services and supports to meet their needs without compromising their safety or wellbeing.
- The NDIA should advise state and territory governments (who have responsibility for housing policy) about the high level of demand for suitable models of housing and work with state and territory governments and the NDIS market to increase housing options for participants.
- The NDIA should review its internal review processes to ensure they are conducive to reaching a desirable outcome for participants, whether that be a change to the original decision or at least a greater understanding by the participant of why a decision was made.
- To ensure an Aboriginal participant's experience of the NDIS is culturally safe and to optimise the participant's engagement with the NDIS and the outcomes they are able to achieve, Aboriginal participants should receive funding for cultural consultants and advisors within their NDIS plans.
- Return to country trips should be appropriately funded in participant's plans to allow Aboriginal participants to maintain their connection to country, culture and community or to explore or increase their connection and to meet any specific cultural obligations in relation to traditional occasions.
- The NDIA should recognise the importance of support coordination for participants involved with guardians and trustees of last resort through the appropriate funding of support coordination services in participants' plans.
- System changes should be made to the NDIS Portal to enable decision makers to access this portal on behalf of participants without this access including access to all other government services linked to the participant's MyGov account.

The PGT welcomes the opportunity to provide further information to the Committee and to address any questions in relation to the PGT's submission and experiences.