

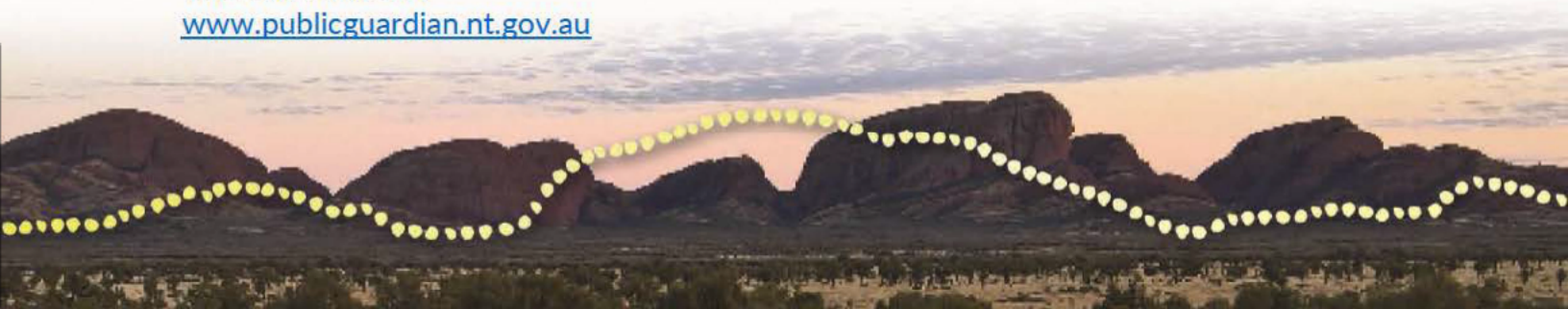


# Northern Territory Office of the Public Guardian Submission to the Joint Standing Committee on the National Disability Insurance Scheme

## SCHEME IMPLEMENTATION AND FORECASTING INQUIRY

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## **Introduction**

The Northern Territory Office of the Public Guardian welcomes the opportunity to provide a submission to the Joint Standing Committee's inquiry into the scheme implementation and forecasting for the National Disability Insurance Scheme (NDIS) for consideration in their final report. This submission is additional to the brief submission provided to the Committee for consideration in their interim report.

The Office of the Public Guardian was established under the *Guardianship of Adults Act 2016*, which provides for the statutory appointment of an independent Public Guardian. The core functions of the Public Guardian are set out in section 61 of *the Guardianship of Adults Act 2016*, and include, but are not limited to:

- being a guardian for an adult when appointed by a guardianship order or acting under section 44 or 45;
- promoting access to support services for adults with impaired decision-making capacity and the guardians, families and carers of those adults;
- encouraging providers of support services to monitor and review the delivery of those services; and
- advocating for adults with impaired decision-making capacity generally, including by promoting understanding and awareness of relevant issues.

The Office of the Public Guardian teams are located in Darwin and Alice Springs and are responsible for providing guardianship services to approximately 604 adults represented by the Public Guardian. Compared to other jurisdictions, the Northern Territory has the lowest number of adults under guardianship orders, however, has the highest percentage of the population under guardianship.

There are approximately 390 represented persons<sup>1</sup> involved with the Public Guardian who are current NDIS participants. The Office of the Public Guardian has attended many, if not 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 capacity<sup>2</sup>.

## **The Northern Territory context**

The Northern Territory context has impacted the implementation of the NDIS across the Northern Territory. The challenges experienced in scheme implementation and forecasting in other jurisdictions are exacerbated in the Northern Territory and demand unique and tailored solutions to meet the needs of Territorians with disability.

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<sup>1</sup>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.

<sup>2</sup> As guardianship orders come into effect when a person reaches the age of 18, all experiences of the Office of the Public Guardian in relation to the NDIS is with participants over the age of 18.

While most Territorians live in regional centres, a significant number live in remote and very remote areas. For Aboriginal<sup>3</sup> people, who make up 30 percent of the Northern Territory population,<sup>4</sup> almost 77 percent live in remote or very remote areas<sup>5</sup>. The Northern Territory population is also comprised of many culturally and linguistically diverse groups.

A small population spread across vast distances poses significant challenges to private and government service delivery and combined with 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.

Approximately 78 percent of people involved with the Office of the Public Guardian identify as Aboriginal. Many speak English as a second or third language with a significant number living in remote communities. The Office of the Public Guardian has observed a disconnect from country and culture, with 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.

### ***Scheme implementation and forecasting for the NDIS***

Proposed scheme implementation and forecasting is challenged by the Northern Territory's unique context. Despite many positive outcomes for participants since the inception of the NDIS, concerns regarding the reduction in funding to participant plans and service provision continue to be a key issue for the Office of the Public Guardian. The current pattern emerging is showing that overall funding provided in plans and support services is decreasing, particularly supported independent living, resulting in NDIS services being unable to provide the level of care and support to enable the participant to live successfully.

The reduction in funding further exacerbates issues already faced by Territorians, especially for participants living in remote areas, who continue to be impacted by the lack of services and access to a full range of allied health professionals. This, along with the variability of experience and quality of service provided by Support Coordinators across the Northern Territory and the high staff turnover and inadequate training for new staff, provides a very challenging environment to provide appropriate supports and care.

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<sup>3</sup> 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*.

<sup>4</sup> Department of Treasury and Finance (NT), Population - Northern Territory Economy: Aboriginal Population (2018) <<https://nteconomy.nt.gov.au/population>>.

<sup>5</sup> Department of Treasury and Finance (NT), Population - Northern Territory Economy: Background (2018) <<https://nteconomy.nt.gov.au/population>>.

The Office of the Public Guardian continues to strongly advocate for appropriate funding for represented persons and has submitted a number of requests for plan reviews and applications to the Administrative Appeals Tribunal. Impacting our advocacy efforts is the lack of legal representation now available to support represented persons at the Administrative Appeals Tribunal. The Northern Territory Legal Aid Commission has been forced to cease providing legal representation for those making appeals to the Administrative Appeals Tribunal due to the exhaustion of their National Disability Insurance Scheme Appeal Legal Service funding. The high demand for their services in this process further highlights the issues being faced by Territorians surrounding NDIS plan reviews and funding reduction. The Northern Territory Legal Aid Commission has sought additional funding from Department of Social Services to enable them to continue providing legal representation at the Administrative Appeals Tribunal, however this has been unsuccessful. This leaves vulnerable Territorians with no avenue to appeal plan funding decisions made by the National Disability Insurance Agency as there is no other organisation providing this service in the Northern Territory.

The Office of the Public Guardian notes the interim report of the Committee released as part of the Committee's General Issues 2021 Final Report. Many of the issues and experiences detailed in the Committee's Interim Report are shared by the Office of the Public Guardian in varying degrees in the Northern Territory. The Committee's recommendation that the Joint Standing Committee on the NDIS reinstate this inquiry following the 2022 Federal election is supported.

The following submissions will address the Committee's Terms of Reference most relevant to the functions and expertise of the Office of the Public Guardian and with reference to the demographic<sup>6</sup> of persons involved with the Office of the Public Guardian.

#### **The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding, including:**

- **the availability of support outside the NDIS for people with disability (community based or Tier 2 supports)**

The availability of support outside the NDIS for people with disability is limited. Since its inception there has been considerable focus and attention on the rollout, implementation and development of the NDIS with a perception that it will provide all supports for people with disability. This has resulted in some withdrawal of support services, including disability coordination services, adult allied health services and quality equipment services provided by the Northern Territory Government for people with disability outside the NDIS, and a decreased impetus to modify mainstream services to ensure accessibility for people with disability.

Submissions of the Office of the Public Guardian to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in relation to the criminal justice system and health care for people with cognitive disability<sup>7</sup> specifically addressed the limited support available

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<sup>6</sup> Persons over the age of 18 years with impaired decision making capacity.

<sup>7</sup> See the Office of the Public Guardian's submission to the Royal Commission's Criminal Justice System Issues Paper, March 2020 and the Office of the Public Guardian's submission to the Royal Commission's Health Care for People with Cognitive Disability Issues Paper, March 2020.

in these settings to meet the physical, emotional and behavioural needs of persons with impaired decision making capacity. Although there is evidence of disability policy in these areas it has often not been realised in practice to ensure people with disability are appropriately supported to access mainstream health and justice services. For people with cognitive disability it becomes very difficult to navigate these and other mainstream services without the assistance of their NDIS supports and services.

Additionally the broader context of disability reform detailed in the former National Disability Strategy 2010-2020 and similar state and local strategies is slow with disability reform traditionally under prioritised within both government and private enterprise. The establishment of the Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability has brought much needed attention to the lives and experiences of people with disability. Its work and recommendations together with the new National Disability Strategy 2021-2031 is hoped to lead to prioritised and strategized disability reform so that people with disability are supported to participate in and access their community and mainstream services.

Importantly, in October 2021 the Northern Territory Government commenced consultations on the Northern Territory's first Disability Strategy. The draft Strategy's vision is that Territorians of all abilities are able to live life to their fullest potential and have quality services no matter where they live<sup>8</sup> with a focus on improving access to mainstream services. It comprises six outcomes driven by action plans to show progress and achievements. A major aspect of the draft Strategy is the NDIS and how the potential of the NDIS can be maximised in the Northern Territory. The Office of the Public Guardian participates in one of the NT Disability Strategy Working Groups and is excited by the commitment of Northern Territory Government agencies to the improvement of the lives of people with disability. This commitment must be met with appropriate human and financial resourcing and must also be replicated across Local Government and private enterprise.

- **the future of the Information, Linkages and Capacity Building grants program**

The Office of the Public Guardian has limited experience of the Information, Linkages and Capacity Building (ILC) programs funded and delivered in the Northern Territory. Despite this limited experience, the four programs within the ILC are noted and supported by the Office of the Public Guardian.

Funded programs to build the individual capacity of people with disability, to provide information on supports and services to people with disability, their families and cares, to improve pathways to employment and improve the capacity of mainstream services to respond to and include people with disability are essential to addressing the limited support for people with disability outside the NDIS. Future programs funded under the ILC should be outcome driven with a specific focus on how the program will meet the needs of people with disability to access supports and services beyond the NDIS. Wherever possible outcomes should be measured and publically available on the NDIS ILC webpage.

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<sup>8</sup>[Northern Territory Disability Strategy | Have Your Say Northern Territory](#) accessed on 28/02/22.

- **The interfaces of NDIS service provision with other non-NDIS services provided by the State, Territories and the Commonwealth, particularly aged care, health, education and justice services;**

The Office of the Public Guardian has evidenced some improvement in the interface of NDIS service provision with other non-NDIS services provided by the Northern Territory and Commonwealth governments. Despite the improvements there is still uncertainty and confusion for stakeholders regarding the supports to be provided within or outside the NDIS and how gaps in supports and services for individuals will be addressed in a coordinated and holistic manner to meet the needs of the individual. On occasions the uncertainty and confusion results in a failure to meet the supports and service gaps in a timely manner and to the detriment of the person with disability. At other times it either results in or is exacerbated by inconsistent decision making by the NDIA.

The Commonwealth and state and territory governments must give a renewed commitment to the funding and delivery responsibilities of the NDIS and other service systems agreed in the Applied Principles and Tables of Support to Determine the Responsibilities of the NDIS and other service systems. This commitment must be accompanied by comprehensive communication strategies for stakeholders and transparent implementation across the NDIS and other non-NDIS services.

#### Aged care

At age 65 people who are not existing NDIS participants are eligible only for aged care supports. There is significant disparity in the level and type of supports available under Australia's aged care system and those supports available to people who are eligible NDIS participants due to impaired cognitive capacity. In effect this is an interface gap that fails to respond adequately to the needs of people who have not sought supports previously under the NDIS or who have an acquired disability later in life (i.e. at age 65 or later).

People with impaired capacity aged 65 years and over who do not require residential aged care and are not existing NDIS participants can struggle to find appropriate accommodation and supports. In the Northern Territory there is a deficit of community based services for this group. There are reports of people waiting 6-18 months for community aged care packages which do not fully respond to or meet their disability/support needs. This leads to people being pushed prematurely into residential aged care at increased human and government cost due to their inability to access supports that would enable them to age in place with dignity. Additionally, residential aged care services are not currently resourced to provide the necessary services and supports to meet the needs of a person with disability aged 65 and over.

#### Health

The Office of the Public Guardian has observed difficulties for people with cognitive disability in the interface between the NDIS and health systems. It can be difficult to attribute if a person's needs arise from a health condition or from their disability which has seen a person's disability needs now being met under the NDIS and not met under the health system due to cost preclusions or unavailability of the health care service.

The NDIS provides that the NDIS may fund reasonable and necessary support to give guidance and training for hospital staff working with a participant if they have challenging behaviours and give specific training to help hospital staff communicate with a participant in they have complex

communication needs<sup>9</sup>. Despite this there is a disconnect in information sharing and coordination of supports between NDIS funded professionals and services and those provided in non-NDIS health settings, including hospitals and outpatient services. It is particularly concerning that relevant and necessary NDIS supports cannot go with the participant when they are accessing in patient services in hospitals. This can result in poor communication between the participant and health providers, the participant's health and emotional needs not being met, the participant displaying behaviours of concern and extended duration of hospital admissions. This has a significant impact upon both the participant's emotional and physical health and the human and financial resources of health services.

A person centred and holistic approach to health care which has consideration to both the person's health and disability support needs and recognises the overall wellbeing of participants will provide for better health outcomes and experiences and a smoother interface between NDIS service provision and health services.

### Justice

As detailed in the Office of the Public Guardian's submission to the Committee's Interim Report, in the last 12 months the Office of the Public Guardian has witnessed a hardening of the NDIA position in respect of the NDIS supports which might be viewed as reasonable and necessary to meet the needs of a person with cognitive disability in the community on release from prison. This can be at odds with the level of supports required to help keep a participant with complex behaviours and the community safe. The Office of the Public Guardian is caught between the conflicting policy positions of Correctional Services and the NDIS in advocating successfully for the interests of the represented persons in such matters. At issue is agreement as to the responsible authority for funding interventions which provide for the disability needs of the person while satisfying the judicial conditions of release.

There are complexities also in the timing and provision of draft participant plans by the NDIS for consideration by the Parole Board of the Northern Territory which may impact an offender's early release. The NDIS will not provide a draft participant plan until a release date has been set by the Parole Board, but it is difficult for the Parole Board to consider how an offender may meet their conditions of parole without details of the funded support that would be included in a draft participant plan. In some instances this will result in a person with cognitive disability who might otherwise meet the conditions for early release being forced to serve out their sentence in full. A level of foresight is also required in respect of NDIS participant plans developed in a prison rather than community setting, which may not meet the individual's ongoing needs.

The interface between justice and the NDIS should be addressed so that participant plans can be built prior to a release date being set for people who are eligible for parole.

### Housing

Appropriate and affordable housing for represented persons is a key area of concern for the Office of the Public Guardian with community and public housing stock remaining in short supply. Since June 2020 the median rental price for houses in Greater Darwin, in particular, has increased

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<sup>9</sup> [Services if you're in hospital | NDIS](#) accessed on 28/02/2022.

steadily, with vacancy rates for houses and units falling in Greater Darwin, Katherine and Alice Springs.

The lack of flexible and affordable housing options for represented persons interacting with justice and health systems, in particular, has consequences. Inappropriate or poorly supervised accommodation options for persons with challenging behaviours can result in a cycle of offending and incarceration and/or longer or indefinite detention. Likewise, delays in sourcing disability ready or age-appropriate accommodation can result in represented persons remaining in hospital for longer than medically necessary at significant public expense.

There must be a commitment from all levels of government to address appropriate and affordable housing options in the Northern Territory to reduce housing waitlist times, increase the level of housing stock that is accessible for people with a disability and create innovative strategies and housing models to reduce the level of homelessness.

**The reasons for variations in plan funding between NDIS participants with similar needs, including;**

- **the drivers of inequity between NDIS participants living in different parts of Australia;**

The drivers of inequity between NDIS participants living in different parts of Australia include:

- the inability of participants to actualize their plan goals through funded services and supports in regional and remote locations where NDIS services and supports are limited or non-existent
  - additional disadvantage that exist for many Aboriginal people and people from culturally and linguistically diverse backgrounds including poverty, language and communication barriers and overcrowded housing
  - the limited informal support networks for some people with disability, including Aboriginal people with disability who have needed to move from their community to access disability or health supports in regional or urban settings
  - the informal and formal support available to participants to know and understand their rights and to advocate for funded support and services and to navigate the complexities of the NDIS.
- **whether inconsistent decision-making by the NDIA is leading to inequitable variations in plan funding; and**

The Office of the Public Guardian has witnessed inequitable variations in plan funding dependent upon the skills and experience of both the NDIA plan manager and the support coordinator, availability of specialist advocates and the formal and informal support network around the participant. A high skill level of either or both the NDIA plan manager and the support coordinator or a strong formal and informal network around the participant has resulted in a more comprehensive NDIS plan for the participant.

Worryingly, there is a general perception among some within the community that participants involved with the Public Guardian will be able to access increased supports due to the advocacy and networks of the Office of the Public Guardian. This perception is particularly concerning as guardianship and the appointment of the Public Guardian as guardian of last resort should not be



perceived as necessary for people with disability to access appropriate and reasonable NDIS supports and services.

- **measures that could address any inequitable variation in plan funding;**

Inequitable variation in plan funding can be addressed by:

- increased transparency of decision making by the NDIA
- accessible NDIS policies and guidelines as both entire documents and in accessible formats
- training of the NDIA workforce to understand and implement the NDIS policies and guidelines consistently
- funded formal advocacy and/or support coordination for participants to understand, access and navigate the NDIS
- simplified processes and procedures within the NDIS to enhance the capacity of participants and their family and carers to access and navigate the NDIS
- addressing market failures with innovative and location specific strategies to ensure participants can receive the supports and services funded in their NDIS plans
- further consultation with Aboriginal people with disability and their representative groups to increase the engagement of Aboriginal people with disability in the NDIS and to determine appropriate strategies and initiatives to deliver NDIS supports and services in remote communities.

The Office of the Public Guardian notes the legislative changes detailed in the *NDIS Amendment (Participant Service Guarantee and Other Measures) Bill 2021* and that it is anticipated that these changes will address some of the above matters by improving NDIS processes and participants' experiences. The success of these changes will need to be measured once they have been implemented into practice.

#### **Financial and actuarial modelling and forecasting of the scheme including;**

- **the role of insurance-based principles in scheme modelling; and**
- **assumptions, measures, and methodologies used to forecast and make projections about the scheme, participants, and long term financial modelling;**

The assumptions, measures and methodologies used to forecast and make projections about the scheme, participants and long term financial modelling have proven to be limited and ineffective in the Northern Territory where there is a small, geographically dispersed population, a high prevalence of disability among Aboriginal people who are also experiencing multiple disadvantage and a limited disability workforce. Consequently, the intended outcomes of competition, innovation and consumer choice and flexibility of a market-based approach have not been realised.

In many parts of the Northern Territory outside Darwin and Alice Springs, there are no or limited NDIS supports and services to meet participants' needs and participants are often required to move from their home communities in order to receive essential supports and services in regional and urban locations. The relocation of participants from their communities, family and other informal supports impacts the participant's cultural and emotional needs and often results in an increased reliance on funded, formal disability support through the NDIS.

In Darwin and Alice Springs market development has been slow and thin markets are still evident for certain types of support including individualised skill development, allied health services,

behaviour support practitioners and supported independent living services that can support participants with behaviour support needs. Often it is difficult to secure the services of a single provider with lengthy wait times and the provider not always possessing the necessary cultural expertise. There is also limited competition among service providers and existing providers are competing for quality workers and professionals from a limited pool, significantly impacting service creation and development. This has been exacerbated during the COVID-19 pandemic with closed borders impacting interstate professionals and workers from either relocating to the Northern Territory or providing a temporary or fly-in services.

Market failure in the Northern Territory means participants are unable to receive supports and services identified in their NDIS plans and therefore unable to reach personal goals that may impact the need and quantity of supports and services in the future. This impacts the scheme projections and financial sustainability.

#### **The ongoing measures to reform the scheme including:**

- **the new early childhood approach, including whether or how early intervention and other supports intended to improve a participant's functional capacity could reduce their need for NDIS funding, and**

There is significant evidence to endorse early intervention and other supports intended to improve a participant's functional capacity and how this can reduce the participant's need for future NDIS funding. Importantly it can also ensure greater decision making autonomy for the participant throughout their life and reduce the need for formal guardianship.

- **planning policy for personalised budgets and plan flexibility.**

The Planning Policy for Personalised Budgets and Plan Flexibility is intrinsically linked to the now abandoned concept of independent assessments. Consequently in its current form it is difficult to provide comment on this policy. However, the Tune Review recommended amendment to the NDIS Rules to clarify that supports in a participant's plan should be used flexibly, except in limited circumstances, such as capital supports. The Office of the Public Guardian supports this recommendation and encourages the NDIA to work closely with people with disability and their representative groups in the further development and finalisation of the planning policy for personalised budgets and plan flexibility to ensure there are no unintended consequences for participants.

#### **Conclusion and recommendations**

Proposed scheme implementation and forecasting is challenged by the Northern Territory's unique context detailed in this submission. Despite this, the NDIS has significantly changed the landscape of disability supports and services in the Northern Territory with many positive outcomes for represented persons. However, these supports and services demand continuous review to ensure that the NDIS continues to meet the evolving needs of participants. This review and any changes to the NDIS to ensure its sustainability must occur in consultation with people with disability and their representative groups.

Recommendations of the Office of the Public Guardian in relation to scheme implementation and forecasting include:

- The Northern Territory Legal Aid Commission should be re-funded to provide legal representation for participants at the Administrative Appeals Tribunal in relation to plan reviews.
- There must be continued initiatives, including the ILC program to support people with disability outside the NDIS to increase access to mainstream services and community engagement.
- The interface of NDIS service provision with other NDIS service provided by states, territories and the Commonwealth must be improved to ensure greater understanding of responsibilities by the participant and relevant stakeholders and to ensure any support and service gaps are identified to meet the needs of the participant.
- The NDIA must continue to explore strategies and initiatives in partnership with people with disability and their representative groups to address NDIS plan inequities and the drivers of these inequities.
- Location specific strategies and funding models must be developed in the Northern Territory to address market failures.