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Joint Standing Committee on the National Disability Insurance Scheme

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Dear Committee

Thank you for providing an opportunity to make a submission on the National Disability Insurance Scheme (NDIS) participant experience in rural, regional and remote Australia.

In 2023, I advocated for extensive stakeholder engagement in a number of remote communities across the Northern Territory where issues related to challenges and barriers to NDIS uptake was discussed. This request was supported and in conjunction with the National Disability Insurance Agency (NDIA), the NDIS Quality and Safeguards Commissioner and representatives from the NDIS Review Panel, we conducted this consultation.

This valued feedback highlighted the critical need for immediate and ongoing communication with participants, carers, families and community representatives about the NDIS and access to the service provider network. Importantly, we heard how this information and engagement should be culturally appropriate, in language and result in quality NDIS plans that reflect participant needs and community priorities.

NDIS participants in remote communities also shared their wish to stay in their community and 'on country' and contribute to community life, however many participants stated that NDIS assessments had little or no understanding of ways to accommodate this need. This is something that we need to change.

Opportunities to support providers to expand their capacity to operate within remote and Aboriginal cultural contexts should be fully explored, along with the establishment of a single consistent point of contact, potentially a shop front in community, for participants and providers to access information and promote better service coordination.

Meaningful choice and control is unable to be fully exercised in regional and remote communities in the Northern Territory due to the challenges participants face in accessing services, as a result of thin, to non-existent markets. High set-up and service delivery costs, lack of connectivity, lack of infrastructure, workforce capability and funding models not fit for purpose in remote areas, all contribute to these thin markets.

The experiences and learnings from ongoing community engagement reinforces the importance of ensuring the Northern Territory Government, the Commonwealth, and the NDIA are, listening, responding, and seeking flexibility in how the NDIS and supporting service systems are rolled out across the Northern Territory and in particular, in its remote communities.

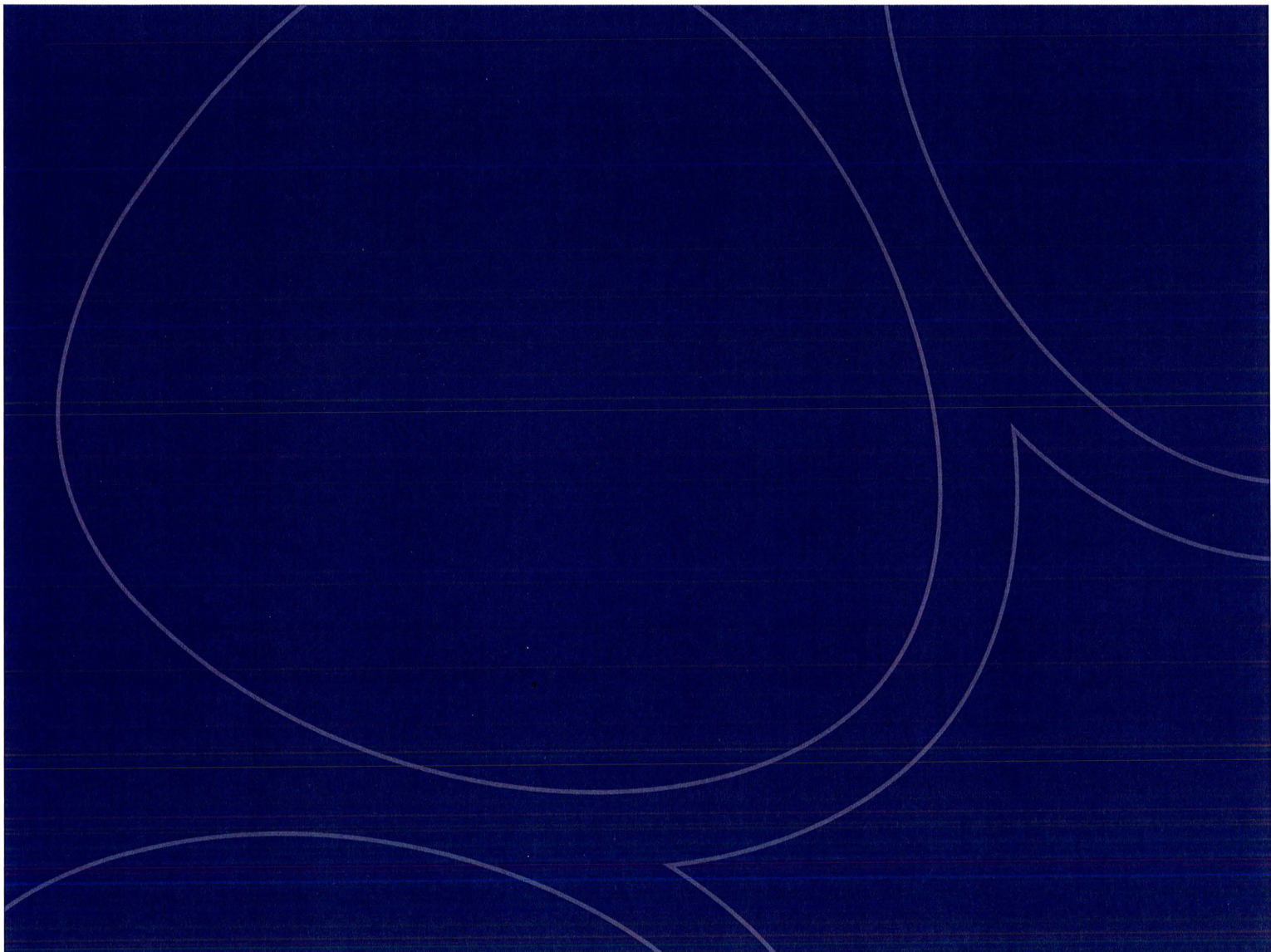
The attached submission provides an overview of the experiences shared by community members in Maningrida and Yuendumu, and reflect the challenges of the NDIS experience more generally throughout the Northern Territory.

Yours sincerely

NGAREE AH KIT

06/02/2024

Joint Standing Committee Submission NDIS Participant Experience in Rural and Remote Communities



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Acronyms	Full form
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NT	Northern Territory
OoD	Office of Disability
TFHC	Territory Families, Housing and Communities

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1. Executive Summary

The National Disability Insurance Scheme (NDIS) provides funding to eligible people who have a permanent and significant disability, to connect them with reasonable and necessary supports to pursue their goals. However, market challenges often limit the ability to deliver the required services and these gaps are particularly evident for both Aboriginal people and remote communities.

In remote and very remote communities, thin markets result in participants receiving limited or no access to support and services. A lack of services in those communities pre-dates the NDIS and has remained a challenge for all levels of government and further contributes to remote residents' limited knowledge of the full potential for disability supports.

The NDIS operates alongside other service systems, including housing, healthcare, education, justice and community safety, transport. The Applied Principles and Tables of Support (APTOS) outlines the roles and responsibilities of mainstream services that deliver services and supports to people with disability and reinforces the obligations of Northern Territory and Commonwealth Government service systems to improve the lives of people with disability. Opportunities to support providers to expand their capacity to operate within remote and Aboriginal cultural contexts should be explored, along with the establishment of a single consistent point of contact, potentially a shop front in community, for participants and providers to access information and promote better service coordination.

The complexities of disability service systems operating in remote communities highlight the critical need for immediate and ongoing communication with participants, carers, families and community representatives about the NDIS and support to access and navigate the service provider network. Importantly, this information and engagement should be provided in a culturally appropriate way, in language and result in quality NDIS plans that reflect participant needs and community priorities.

Consistent and ongoing local engagement in community is required to ensure the Northern Territory Government, the National Disability Insurance Agency (NDIA), and the NDIS Commission are listening, responding, and seeking flexibility in how the NDIS and supporting service systems are rolled out in all remote and very remote communities.

2. The NDIS in the Northern Territory

There are 5,853 NDIS participants in the Northern Territory, as at 30 September 2023.

The NDIS provides eligible participants with funding to access services provided by registered and non-registered providers enabling people with a significant and permanent disability to live an ordinary life through:

- Supporting their independence and social and economic participation by providing reasonable and necessary supports; and
- Opportunities to exercise choice and control in the pursuit of goals, planning and delivery of their supports.

The NDIS operates within an open market arrangement aimed at giving people with disability the support required to exercise choice and control to access reasonable and necessary supports, via diverse and sustainable providers that offer a full range of quality supports wherever people live.

Meaningful choice and control is unable to be fully exercised in regional and remote communities in the Northern Territory due to the challenges participants face in accessing services, as a result of thin to non-existent markets, even with the NDIS. High set-up and service delivery costs, lack of connectivity, lack of infrastructure, workforce capability (with less reliance on FIFO delivery) and funding models not fit for purpose in remote areas, all contribute to these thin markets.

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In addition, people with autism, psychosocial or intellectual disability may not be identified at the interface between health/education/justice and disability services due to the fact that they are able to continue with daily life. Even people that do come to the attention of the NDIS, may not, or their family may not, be willing to participate in the assessment process and if consent is obtained, they also may not be engaged in the process, particularly where language barriers exist.

The number of NDIS participants across the Northern Territory are often lost or viewed as insignificant against other jurisdictions, due to perceived low numbers. While the Northern Territory represents 1 per cent of the total NDIS participants across Australia, it has the highest proportion of NDIS participants identifying as Indigenous (50 per cent). Of that figure, 38 per cent of those NDIS participants reside in remote communities.

Period	Status	Australia	% of pop	Northern Territory	% of pop
Q1 FY23/24	Indigenous	48,966	7.75%	2,950	50%
Q1 FY23/24	Non Indigenous	487,969	77%	2,429	41%
Q1 FY23/24	Not Stated	94,597	15%	474	2%
Q1 FY23/24	Total	631,529		5,853	

Prior to the NDIS, the Northern Territory Government's specialist disability service functions and funding was delivered by the Office of Disability. The Office of Disability historically provided mainstream service functions for community allied health (physiotherapist, speech therapist and occupational therapist), low to medium level support needs and specialist disability needs.

The NDIS operates along other service systems, including housing, healthcare, education, justice and community safety, and transport. The Northern Territory Government's current role includes:

- Support to the Commonwealth and engagement with people with disability, their families and carers, on ongoing refinement of the policy of the NDIS, including its interface with other service systems and non-government and community-based supports.
- Coordination and promotion of links between the NDIS and other service systems and non-government and community-based supports to create seamless delivery of supports to NDIS participants.

The Office of Disability, within Territory Families, Housing and Communities (TFHC), supports Territorians with a disability, including those that are not eligible for the NDIS, through:

- Whole of government disability policy and program development;
- Ongoing contribution to the implementation of the NDIS in the Northern Territory and monitoring and reporting against the NDIS;
- Grant funding to organisations for the provision of peak body operations, advocacy and information services, and disability awards programs; and
- Secretariat and support to the NT Disability Advisory Committee and the Disability Reform Ministerial Council.

Despite the Northern Territory's transition to the full scheme of the NDIS commencing on 1 July 2016 and full scheme implementation on 1 July 2019, feedback from communities has highlighted a lack of awareness and understanding of the NDIS in many remote areas, and low access and utilisation of plans in the community. There is also a general lack of understanding of the broader mainstream disability supports outside of the NDIS available in those remote and very remote communities.

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The Northern Territory is a small, culturally diverse, dispersed population over a large remote geographic footprint, and has a unique remote service delivery operating context. As a result, the Northern Territory and Commonwealth Governments have agreed that the Northern Territory's approach to the NDIS will be guided by the principles that recognise the importance of placed-based, tailored solutions to planning, market development and service access, while supporting risk management and coordinated and culturally competent engagement and service responses.

In August 2023, Minister for the NDIS, the Hon Bill Shorten MP, announced Maningrida as a site for an Alternative Commissioning trial to strengthen the access and utilisation of NDIS in remote communities. The trial site is expected to attract around \$4 million of investment to Maningrida and will be designed to enable the community to identify new and innovative ways to bring disability services to communities that have historically not been able to access the services they need. The project will be jointly developed and implemented by the NDIA and Northern Territory Government in collaboration and partnership with local community members and community controlled organisations to harness opportunities for improved outcomes for people with disability living in remote and very remote communities across the Northern Territory.

2.1. NDIA Rural and Remote Strategy

The NDIA Rural and Remote Strategy (the Strategy) was developed in 2016 to guide the roll out of the NDIS in rural and remote Australia during transition. The Strategy recognised that people with disability in rural and remote Australia, including First Nations people, might require additional support to access the NDIS, receive an NDIS plan and use their supports appropriately.

The NDIA's current approach to remote service delivery aims to deliver:

- Quality participant plans with the inclusion of supports that are culturally relevant.
- Improved social and economic outcomes for participants by addressing existing supply gaps at a local level, including the use of alternative commissioning for supports where required, and improved coordination between disability and mainstream services.
- Coordination across all levels of government to maximise the outcomes of the NDIS, recognising that it is part of a broader government service delivery ecosystem in remote communities.
- Access to specific service types or markets at a whole-of-region level through thin market trials and alternative commissioning approaches.
- Improved outcomes at a whole-of-community level by implementing a place-based approach that delivers participant outcomes and facilitates solutions.

To support this approach, the following key measures are promoted in remote Australia:

- Remote Community Connectors - As trusted community members, Community Connectors play a critical role in identifying and engaging with people with disability and their representatives. It is noted that there are currently no Remote Community Connectors operating in Maningrida.
- Higher price limits for supports in remote and very remote areas - The NDIS Price Guide allows higher price limits for some supports in remote and very remote areas as a response to higher operational costs to deliver services in these areas.
- Improving NDIS services delivered by Aboriginal Community Controlled Health Organisations aimed at increasing the supply of culturally appropriate and localised NDIS supports for Aboriginal people with disability. For example, Malala Aboriginal Medical Service in Maningrida is a registered provider of NDIS Services.
- Thin market trials – aimed to identify and trial more flexible approaches to address market challenges with the NDIS associated in rural and remote locations.

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All stakeholders have acknowledged that the intent of the Strategy is to support and promote culturally appropriate service delivery and improve the overall uptake of NDIS for people with disability in remote communities, however unfortunately this appears not to have occurred in many Northern Territory regions.

3. Independent Review of the NDIS

The Independent Review of the NDIS was announced by the Hon Bill Shorten MP, Minister for the NDIS, in October 2022. The objective of the review was to put people with disability back at the centre of the NDIS, restoring trust, confidence and pride in the NDIS, while ensuring the sustainability of the scheme. The NDIS Review final report was publically released on 7 December 2023.

The Independent Review Panel visited the Northern Territory from 4– 9 June 2023. The review engaged with key stakeholders in metropolitan, remote and very remote communities including Darwin, Maningrida, Groote Eylandt, Tennant Creek, Ali Curung and Alice Springs.

The Independent Review Panel's visit to Maningrida was on 5 June 2023, where they met with a number of key stakeholders (Attachment 1 provides a summary of NDIS Panel findings from their visit to the Northern Territory).

The deep dive project and the NDIS Review Panel's approach noted activities and timeframes that would benefit from a collaborative approach between TFHC and the Independent Review Panel.

As a result, a community engagement workshop was convened in Darwin on the evening of 5 June 2023 where many of the concerns and barriers to proactive and productive service delivery, including to remote and very remote communities, were discussed. Many of the issues raised were consistent with the observations of the panel from their visits to remote communities in the Territory.

General observations from service providers include:

- Lack of trust in the NDIS program, as many participants feel that they may have access to services one day, only to have the service removed or re-assessed as 'unnecessary' the next.
- Concerns as to the transparency and independence of Coordinator of Support for participants, particularly if they operate outside of the Northern Territory.
- NDIS undermines community programs and does not encourage a step up/step down type program.
- NDIA representatives remain hidden and assess from a distance, with little or no cultural sensitivity.
- Lack of development and training of a local community based workforce in support participants.

4. 2023 NDIS Deep Dive Project in Remote Communities

In December 2022, the Hon Ngaree Ah Kit MLA, the Northern Territory Minister for Disabilities, committed to undertake a community-led pilot project to better understand the low uptake and utilisation of the NDIS by people with disability in remote and very remote communities in the Northern Territory. Maningrida and Yuendumu were identified as the two remote communities in which to undertake this work.

The project was led by TFHC in collaboration with the local representatives from the NDIA and the NDIS Quality and Safeguards Commission. The Minister requested the formation of the Interagency Disability Working Group (Working Group) to focus on improving the uptake of NDIS approved supports among people with disability in the Northern Territory, focusing on NDIS funding and recipients within Maningrida and Yuendumu.

Prior to the activation of the Working Group, steps were undertaken to ensure a community-led and informed approach for the project which included the establishment of local relationships and links to existing community based service delivery. This included coordination of structures and processes, engagement with local service delivery representatives to gain a conceptual understanding of the issues,

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and consultation with advocacy groups with local links and/or membership to gain a complete understanding of current experiences, wants and needs of NDIS participants.

Stakeholders and community members, including NDIS participants, local community service organisations and NDIS service providers, raised and discussed a number of key issues at the consultation and engagement sessions. Face-to-face sessions were held in community with the Northern Territory Minister for Disabilities and the NDIS Quality and Safeguards Commissioner Tracey Mackey.

From this feedback, the conceptual understanding of the issues faced in utilisation of NDIS funding as well as an opportunity to explore the needs and wants of NDIS participants in Maningrida and Yuendumu were identified and outlined.

One example of the significant issues raised is when NDIS participants wish to stay in their community and 'on country' and contribute to community life, NDIS assessments had little or no understanding of ways to accommodate this need, and were unable to fulfil their requests.

It is acknowledged that many, if not all, remote and very remote communities experience similar issues and concerns around gaps in service delivery, which are often communicated through local advocacy forums.

It is anticipated that following the release and commencement of implementation of the recommendations of the NDIS Independent Review, along with the findings from the Deep Dive project, the Working Group will undertake the following, in collaboration with local stakeholders:

1. The assessment of the overall current state via the collation of information and prioritisation of issues.
2. The design of the future state based on priority issues and development of pathways forward to improve outcomes based on the NDIS Review recommendations.
3. Implementation of the planned and recommended actions in the future state.

5. Local Decision Making

Local Decision Making (LDM) is a Northern Territory Government commitment to provide opportunities to transfer government service delivery to Aboriginal Territorians and organisations, based on their community aspirations. The LDM framework was endorsed in August 2018. The LDM Policy's guiding principles are self-determination, flexible place-based approaches, co-design and community control.

The Department of the Chief Minister and Cabinet (CM&C) coordinates whole of government engagement for LDM and is also responsible for negotiating the agreements with the relevant Aboriginal Corporations stakeholders, and community members.

The LDM agreements set out the social and economic agenda for the region over an agreed period of time and sets the foundation for working together on local priorities with community leaders and organisations and Northern Territory and Commonwealth Governments.

A key component of LDM agreements is the establishment of a single local cultural governance group to act as the first point of call for governments to consult when forming policy decisions affecting the community and surrounding regions. These groups are aimed at having the power to make decisions and set priorities for economic and social development in the best interests of the community.

Opportunities to incorporate NDIS service delivery in future LDM negotiations will ensure that culturally appropriate services are developed and are responsive to the specific needs of a community and to the people living with disability in that community. This will be particularly valuable to help build capacity for remote communities to deliver NDIS services through Aboriginal Community Controlled Health Organisations, as identified in the NDIA Rural and Remote Strategy.

As at January 2024, there are currently 13 signed LDM Agreements at various stages of implementation and 28 draft Agreements in development, including for Maningrida and Yuendumu.

6. Maningrida

Maningrida is an Aboriginal community in the heart of the Arnhem Land region of the Northern Territory. Maningrida is 500 kilometres east of Darwin and has a population of 2,956 (2021 census) comprising at least 5 language groups: Ndjebbana, Kunwinjku, Maung, Djambarrpuyngu, and Kriol.

At the time of the deep dive in April 2023:

- There were 75 NDIS participants living in Maningrida, 93 per cent of which identify as Indigenous/First Nations, and 63 per cent identified as Culturally and Linguistically Diverse (CALD).
- 13.5 per cent are caring for a person with disability, health condition or old age.
- The average annualised plan total was \$56,086, with the usage of these funds being 36.5 per cent.
- There were 18 NDIS Registered Service Providers who had been paid for service at least once during the first three quarters of the 2022-23 Financial Year.

Aboriginal community controlled organisations play an important role in providing a range of services, and programs to the communities within the West Arnhem region.

The community is currently developing a Local Decision Making (LDM) Agreement with the Northern Territory Government. A key priority of the LDM will be the establishment of a single Community Governance Group with the cultural authority to engage with Commonwealth and Territory Governments.

The key Aboriginal community controlled organisations in the community are:

- Mala'la Health Services Aboriginal Corporation – provides culturally appropriate and comprehensive primary health care service to Maningrida community and surrounding homelands.
- Maningrida Progress Association (MPA) – is responsible for the two local general stores – the store is a community-based enterprise with profits directed back into the community. MPA also run the motel, fuel access and the Maningrida Airport.
- Dhukurri Development Corporation – provides accommodation – Dhukurri Lodge. Aligned to the vision of the Dhukurri clan.
- Bawinanga Aboriginal Corporation (BAC) – organisation assists over 4000 people of the homelands surrounding Maningrida in the West Arnhem Region. BAC operate a number of retail businesses and the services and infrastructure provided are – housing, land management through Bawinanga Rangers, Babbarra Women's Centre, nursery, Wild food Café, Community Development Program and a civil works program.

Cultural Governance Group

- Nja-Marleya Cultural Leaders and Justice Group – consists of leaders of the Maningrida community with cultural authority who are representative of the language groups of the region.

Other key groups are:

- West Arnhem Regional Council (WARC) – Provides strategic direction and core services to five communities. WARC is one of the largest employers in the region and its core municipal services include waste management, maintaining roads and parks.

TFHC, NDIA and the NDIS Quality and Safeguards Commission worked collaboratively on the deep dive of Maningrida in April and June 2023, with numerous engagement activities undertaken both in Community and remotely.

The NDIS Quality and Safeguards Commissioner and the Minister for Disabilities also directly engaged with the community through face to face visits and via a remote Service Provider Workshop. One on one discussions were also held with participants and a number of their family members to discuss concerns in confidence.

7. Yuendumu

Yuendumu is a community largely made up of the Walpiri and Anmatyerr Aboriginal people. It was established in 1946 by the Native Affairs Branch of the Australian Government to deliver rations and welfare services. In 1947 a Baptist mission was established there and by 1955, many of the Walpiri people had settled in the town. Yuendumu retains links with other Walpiri communities within the region, including Lajamanu, Willowra, Yuelamu and Nyirripi.

Yuendumu, classified as 'very remote' and is located 290 kilometres north-west of Alice Springs, a journey of around 3 hours, along the Tanami Highway. There are a large number of Outstations surrounding Yuendumu. The population of Yuendumu is approximately 740 people (based on the 2021 Census) of whom 83.4 per cent identified as of Aboriginal or Torres Strait Islander descent.

At the time of the deep dive:

- There were 16 NDIS Participants living in Yuendumu, 87.5 per cent of which identified as Aboriginal.
- 13 per cent are caring for a person with disability, health condition or old age.
- The average annualised plan total was \$71,813 with the usage of these funds being 51 per cent.
- There are 12 registered providers operating services in Yuendumu, who had been paid for service at least once during the first three quarters of the 2022-23 Financial Year, providing a range of services including support coordination, Assistive Technology, Transport and Capacity Building Supports.
- There are no NDIS Early Childhood Partners or Local Areas Coordination Partners.

The key Aboriginal community controlled organisations in the community include:

- Southern Tanami Kurdiji Indigenous Corporation - provides mediation and justice services and community safety patrol services to Yuendumu and Willowra communities.
- Wanta Aboriginal Corporation – provides range of youth services and support activities aimed at improving school attendance and vocational opportunities through sport, recreations and cultural activities.
- Warlukurlangu Artists Aboriginal Corporation - supports the artists from Yuendumu and the neighbouring Warlpiri communities of Nyirripi and Yuelamu.
- Warlpiri Media Aboriginal Corporation - 30 years of experience creating TV, radio and music in Yuendumu, working with local people in language, PAW Media and Communications is a not-for-profit organisation.
- Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (Purple House) - Operating from its base in Alice Springs in the Northern Territory - provides a non-residential aged care program in Yuendumu.
- Yapa-Kurlangu Ngurrara Aboriginal Corporation (YKNAC) - is a Warlpiri organisation based in Yuendumu. Established in 2015, it maintains and upgrades homelands infrastructure in the Tanami region. It is also seeking to extend its essential services work and to set up a construction arm.
- Yuendumu Women's Centre (YWCAC) - is a resource centre and provider of advocacy services for the women of Yuendumu and their families. The YWCAC provides culturally appropriate community led support for women, particularly in respect of Family and Domestic Violence services.

Other key groups are:

- Central Desert Regional Council (CDRC) - The Central Desert Regional Council comprises nine communities or Council Delivery Centres. The CDRC provides municipal services and communities services including CDEP and youth services.

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A face-to-face stakeholder engagement session was held in Yuendumu on 16 August 2023 by the NT Minister for Disabilities and the NDIS Commissioner for Complaints. These discussions provided an opportunity to listen and learn from people with a disability, families and carers, service providers, Traditional Owners and community members, of their lived experiences with the NDIS.

The consultations were led by the NT Minister for Disabilities and the NDIS Commissioner for Complaints. Representatives from the Northern Territory office of the NDIA and TFHC also participated in the sessions, and one to one discussions were held with participants and family members where they were unable to attend scheduled events, or preferred to speak in confidence.

8. What we heard in Maningrida and Yuendumu

The key themes for both remote communities' highlighted similar concerns and are captured below:

Key themes	What Stakeholders said
Participants	<ul style="list-style-type: none"> • Difficulty is faced by participants and their families to seek support and navigate the NDIS service provider network. • There is sometimes confusion by participants on what is included in their NDIS Plan. • Participants rely on fly in fly out (FIFO) workers to provide therapy services – infrequent visits are costly, quickly drawing down on participants' plans and services often do not meet clients' needs. • Respite services are off community and do not accommodate family which often places further stress on families. • Informal supports, in particular, family members, provide much needed support to people with disability, without support or financial recognition. • Participants have identified a lack of equipment maintenance services in the communities, which is problematic for people in wheelchairs that need servicing or repair. • Participants have to tell their story more than once when they change service providers and it is not always a good spend of their NDIS plan funding. • Participants want to stay in their community and 'on country', which is not well understood or accommodated in an NDIS plan.
Providers	<ul style="list-style-type: none"> • It is highly costly to service remote communities and plan funding does not fully meet the needs of participants, also affecting provider viability. • Community services cannot identify who is providing supports for NDIS participants, or whether specific community members with disability are engaged with NDIS. • There is a lack of separation between intermediaries and support providers which may lead to sharp practices. • The frequency of visits by providers is poor, resulting in under servicing and missed opportunity for good care by participants. • There was evidence that some service providers worked together to maximise outcomes for participants, but there are many still who work in silos resulting in uncoordinated care.

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Key themes	What Stakeholders said
NDIS	<ul style="list-style-type: none"> The NDIS is complex and there is a lack of knowledge or understanding of the NDIS. The NDIS access and planning process is complex and difficult. There are limited opportunities for early intervention due to an inability to access assessment services and insufficient support for families and children to access early childhood intervention services. Support coordinators that are not based on community are not engaging participants with daily services and supports needed on community. All stakeholders acknowledged the lack of services across the region and in smaller communities and homelands in particular. It was identified that there is limited choice for people living with disability. There is fragmentation of roles between intermediaries on community and off Community. Market gaps result in people with disability accessing limited or no supports (including Tier 2 supports). Community members are worried about accessing the NDIS in fear of becoming involved with the child protection system.
Mainstream Interface	<ul style="list-style-type: none"> There is a lack of appropriate housing for people with disability on community and it is unclear how the NDIS and mainstream services work together. Information sharing between the NDIS and mainstream services contributes to confusion and siloed service delivery. Tools like Bushtel has the potential to assist planning and collaboration between service systems and providers. Existing infrastructure does not always support accessibility and inclusion (i.e. children miss out on school because of no school bus, limited footpaths and poorly maintained roads). Community members are unclear what the relationship is between the NDIS, other disability service providers and the aged care system. <p>In Yuendumu there was a particular focus on the following issues:</p> <ul style="list-style-type: none"> People with cognitive disability who interface with the justice system are not always supported to navigate the complex justice system. Early Learning and education settings provide an opportunity for early intervention supports i.e. through the use of childhood screening tools like ASQ TRaK used in the Families as First Teachers Program and Health Under 5 Partnering with Families Program delivered by NT Health. Community members may not engage with the local health clinic, due to the turnover of staff and having to rebuild the trust and tell their story again. Housing new builds and the Room to Breathe Program could better assist family members to provide support and allow families to live together. There is a need for more accessible disability toilets in community settings

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Key themes	What Stakeholders said
Workforce	<ul style="list-style-type: none"> Attracting and retaining staff is challenging in remote communities. There is a lack of long term housing for providers wishing to develop a permanent presence on community. FIFO models of care are expensive and do not support engagement with community members and local organisations. There is a lack of options to train and support a local Aboriginal workforce. Local community members who provide NDIS funded services on community have added expectations to provide services they are not funded for. Community based organisations and local community businesses/social enterprises that could potentially provide disability support services but they have difficulties in understanding the NDIS system – and often choose not to deliver disability supports due to the complexity of the registration and claiming process. There is shortage of allied health staff, particularly in remote locations which delays assessment and access requests to the NDIA.
Culture and Community	<ul style="list-style-type: none"> Participating in community, culture and country is important for participants and their families. There is a need for information and communication about the NDIS and mainstream services in local languages - which contributes to less than optimum engagement with service providers. There are local interpreters in Community, however these are not always being used by service providers to facilitate engagement with people with disability and their families. Community based organisations supporting arts and culture have good uptake and provide opportunities to increase participation of people with disability (social supports). Culture and kinship ties are strong in Maningrida. Extended families are sharing the care of relatives with disability and provide a range of informal supports including cooking, cleaning, personal care, administering medication and transport.
Other	<ul style="list-style-type: none"> All stakeholders acknowledged the lack of services across the region and in smaller communities and homelands in particular. It was identified that there is limited choice for people living with disability. There is a significant lack of local presence of intermediaries (Coordinator of Supports, Remote Community Connectors, Plan Managers, Local Area Coordinators). The Local Decision Making Framework being implemented by the NT Government provides an opportunity to streamline and coordinate efforts towards community-led priority setting.

9. Possible reform opportunities

Through the extensive consultation and discussion with stakeholders and community members, including NDIS participants, local community service organisations and NDIS service providers across the Northern Territory, the potential reform opportunities set out below were identified.

These ideas build upon the recommendations from the NDIS Independent Review and will require discussion and consultation with the Working Group and stakeholders on the ground, and include community endorsement through appropriate cultural governance groups and mechanisms locally across the Northern Territory.

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Key themes	Possible reform opportunities
Participants	<ul style="list-style-type: none"> • Increase engagement with participants in local language to improve knowledge and support access to the NDIS. • Grow NDIA local presence in community to support access processes and scheme navigation.
Providers	<ul style="list-style-type: none"> • Enable providers to employ local people to support culturally appropriate service delivery. • Support providers to expand their capacity to operate within remote and Aboriginal cultural contexts. • Incentivise providers to have a greater presence on community and reduce fly in fly out service models.
NDIS	<ul style="list-style-type: none"> • NDIA to provide consistent and culturally appropriate communication to participants to increase their knowledge of the NDIS. • Increase support for assessment and access to NDIS that reflects community needs. • Alternative commissioning - the place-based, community-driven alternative commissioning pilots will be underpinned by positive partnerships between market options, participants and communities within existing cost and funding frameworks. These solutions will be co-designed from the ground up through collaboration with community • Recognise the role of families caring for NDIS participants and consider formal employment arrangements to support this.
Mainstream Interface	<ul style="list-style-type: none"> • Improve the understanding of mainstream services about the NDIS and the roles of the NDIA and NDIS Quality and Safeguards Commission. • Increase engagement between mainstream services, Aboriginal community controlled health services and the NDIA to ensure more effective service protection. • Improve data and information sharing between mainstream services, the NDIA and the NDIS Quality and Safeguards Commission. • Consider housing options to incentivise greater presence on community by service providers.
Workforce	<ul style="list-style-type: none"> • Train local community members to deliver NDIS services. • Establish strategies to grow and retain a carer workforce for ageing and disability. • Establish an NDIA Remote Community Connector program.
Community and Culture	<ul style="list-style-type: none"> • Maximise partnerships through the NT Government Local Decision Making Framework to support streamlined decision making and governance. • Recognise the strength and importance of culture and staying on country for health and wellbeing for NDIS participants.
Other	<ul style="list-style-type: none"> • Establish a single, consistent point of contact, potentially a shop front in community, for participants and providers to access information and promote better coordination.

10. Conclusion

As reflected in this submission, the complexities of the disability service systems operating in remote communities has highlighted a need for immediate and ongoing communication with participants, carers, families and community representatives about the NDIS and necessary support to access and navigate the service provider network. It is imperative this information and engagement should be provided in a culturally appropriate way; in language and must result in quality NDIS plans that reflect participant needs and community priorities.

The shared stories from stakeholder groups and people with disability about the lack of services in the remote regions, identified a need for flexible strategies to be co-designed to reflect local needs and circumstances to overcome the barriers the Northern Territory continues to face in the uptake of the NDIS. To do this, local community control and governance must harness opportunities for improve outcomes, and ensure appropriate responses and flexibility of service delivery for people with disability living in the Northern Territory and in remote and very remote communities more broadly.

The Northern Territory Government welcomes the announcement of the Alternative Commissioning trial in Maningrida to identify new and innovative ways to bring disability services to a community that has historically not been able to access the services they need. The strength of the program will be that it is jointly developed and implemented in collaboration and partnership with local community members and community controlled organisations.

The Bilateral Agreement which outlines the roles and responsibilities of the Commonwealth and the Northern Territory Government in the delivery of the NDIS, aims to achieve the objectives as set out in the *National Disability Insurance Scheme Act 2013*. Recommendations from the Disability Royal Commission and the NDIS Independent Review will guide future negotiations the Northern Territory Government will have with the Commonwealth, particularly related to any changes in the NDIA Rural and Remote Strategy. Additionally, negotiations must include the consideration of culturally appropriate services to improve community members' access to the NDIS, and opportunities to build capacity for increased coordination between remote disability and mainstream services, wherever possible.

As the Northern Territory Government commences work with to implement these recommendations, the experiences and learnings from ongoing community engagement reinforces the importance of ensuring the Northern Territory Government, the NDIA, and the NDIS Commission are, and will continue to be, listening, responding, and seeking flexibility in how the NDIS and supporting service systems are rolled out across the Northern Territory and in particular, in its remote and very remote communities.

Attachment 1 – Independent Review of the NDIS – NT Findings

Summary of key findings from the NDIS Review Panel visit to the Northern Territory:

Key themes	Possible reform opportunities
<ul style="list-style-type: none"> • The NDIS access and planning process is complex, difficult and inequitable • There is a lack of trust and engagement with the NDIA • First Nations disadvantage and culture is not properly recognised and understood • The NDIS is not effectively integrated with mainstream and community 	<ol style="list-style-type: none"> 1. Simplifying the access process for children, including the expanded use of ASQ track 2. Increase face to face engagement with participants, families and carers, and provide greater opportunities to discuss the plan 3. Provide greater plan flexibility for participants, such as making it more flexible for participants to move in and out of urban and remote settings, and take a more considered approach to plan utilisation 4. Provide greater clarity on reasonable and necessary 5. The NDIA to increase community engagement on the NDIS, including the access process and pre-planning 6. The NDIA to increase physical footprint and presence in rural and remote communities and increased employment of First Nations staff 7. Increased investment in and implementation of culturally safe child screening and implementation programs such as Connected Beginnings and Families as First Teachers. 1. Explore partnerships with the National Indigenous Australians Agency and the Northern Territory Government, including as part of Closing the Gap and Central Australia Executive Regional Controller initiative 2. Local and community based governance models 3. Better leverage and acknowledge the capability, connections and infrastructure of existing First Nations organisations and initiatives 4. Increased face to face engagement with participants, families and carers in culturally appropriate settings 5. Consider the expansion of the Remote Community Connector Program or similar functions 6. Consider the expansion of liaison officers or similar functions in housing for First Nations communities 7. The NDIA to review and strengthen First Nations employment strategies within the agency and training initiatives for culture and practices 8. The NDIA to review current policy and practices regarding on country visits and use of interpreter services 1. Proactive integration between the Commonwealth, across State/Territory and local governments, underpinned by strong local governance. 2. The NDIA to increase engagement with mainstream services (in particular early childhood, education, health and housing) and community organisations – with a particular focus on the access process 3. Clarifying the roles and responsibilities of the NDIS and mainstream services 4. Improve information and data sharing between the NDIA and mainstream service providers (for example the electronic health records)

Key themes	Possible reform opportunities
<ul style="list-style-type: none"> • There are significant support gaps leading to people with disability going without help • Individualised funding has unintended consequences for people with disability and local communities • Workforce challenges are unique in rural and remote and First Nations communities 	<ol style="list-style-type: none"> 1. Explore alternative commissioning such as direct commissioning, indirect commissioning and community led community, and opportunities to trial in remote and very remote communities 2. Targeted engagement with rural and remote communities to increase service provider numbers and capability to deliver and claim services under the NDIS 3. Consider a community coordinator of supports, or similar, that would have visibility of plans across a particular community (such as Maningrida) – this would enable improve coordination of service providers and opportunities to pool resources across plans (if required). 4. Workforce mapping and strategy across rural and remote communities to identify areas of shortage and develop collaborative solutions across providers and service types 5. Simplification and potential consolidation of intermediaries in rural and remote settings, such as coordinators of support and plan managers 6. Strengthen quality and safeguarding provisions for participants, such as greater visibility/transparency of service and accountability for coordinators of support for underutilisation of supports 7. Reduce the frequency of therapy assessments required by the NDIA – particularly in communities that have limited therapists 8. Provide incentive payments for providers to deliver supports in place (in remote settings), rather than FIFO 9. Provide incentives and support for First Nations communities to complete disability related qualifications, including allied health 10. Explore opportunities for the employment of family members, where appropriate, particularly in rural and remote and First Nations contexts