

22 February 2024

Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600
Email: ndis.joint@aph.gov.au

Dear Chair and Committee Members,

NDIS participant experience in rural, regional and remote Australia

Thank you for the opportunity to provide input in relation to the inquiry regarding rural, regional and remote experiences with the NDIS. We note the terms of reference for the current inquiry are to:

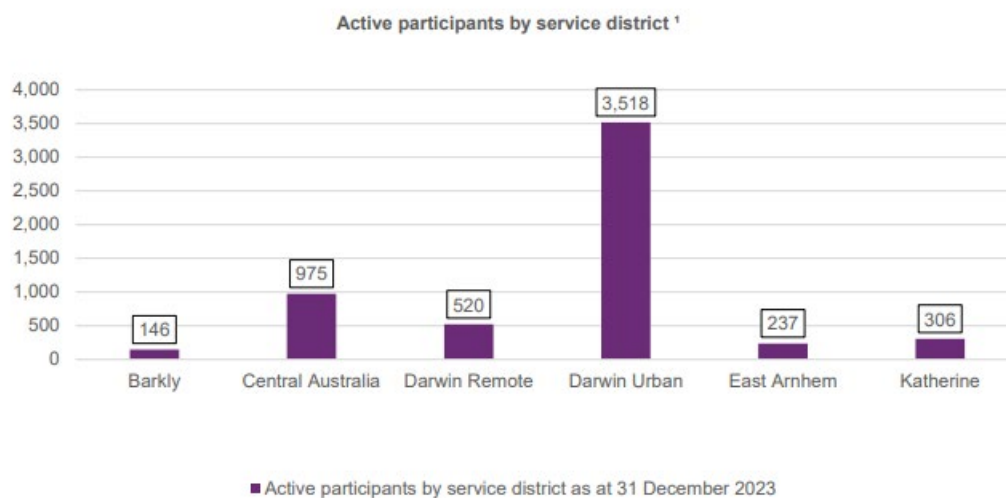
‘inquire into and report on the NDIS participant experience in rural, regional and remote Australia, with particular reference to:

- a. the experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews;
- b. the availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional and remote participants;
- c. participants’ choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services;
- d. the particular experience of Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds, and participants from low socio-economic backgrounds, with the NDIS; and
- e. any other related matters.’¹

2023 has been a significant year for people with disability in Australia, with the recommendations made by Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, as well as the NDIS Review. We appreciate the Joint Standing Committee’s engagement with the extensive submissions made into your inquiry into capability and culture of the NDIA. Darwin Community Legal Services has provided extensive submissions previously on the experience of (prospective) NDIS participants in the NT. This submission to the Joint Standing Committee on the National Disability Insurance Scheme highlights the experience and distinct challenges of rural, regional and remote (RRR) NDIS participants in the Northern Territory (NT). By virtue of our geography, the discrepancy between urban NDIS participants and RRR participants significantly impacts Territorians. As noted in the most recent update from the NDIS Scheme Actuary office, even within the Northern Territory there is a large difference between active participants by service district:

¹ Accessed on 19 January 2024 at:

https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/RuralRegionalandRemote/Terms_of_Reference



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Experiences of people with disability in RRR areas when they have made access to the scheme are of limited provider choice and control. The RRR areas are marked by low plan utilisation, and high market concentration. Both East Arnhem and Darwin Remote service districts scoring just over 50% of plan utilisation.³ The Katherine and Barkly districts score between 70% and 85% of payments going to the 10 largest providers.⁴

The case studies in this submission illustrate disparities in service access, quality, and effectiveness compared to urban areas. Our recommendations focus strategic investments to address the unique barriers faced by remote NDIS participants, ensuring equitable service provision across all regions, and on substantial funding increases for advocacy programs and additional dedicated resources for legal assistance.

About DCLS

Darwin Community Legal Service ('DCLS') is a non-profit community-based organisation committed to legal and social justice and the protection and expansion of rights, fairness, and wellbeing in the Northern Territory.

DCLS is the only generalist community legal service in the NT and is the only non-profit legal service which specifically aims to assist older people and people with a disability.

The main services within DCLS are the General Legal Service (GLS), the Seniors and Disability Rights Service (SDRS) and the Tenants' Advice Service (TAS). Some programs are NT-wide, and others are

² Northern Territory Quarterly Performance Dashboard 31 December 2023, NDIS. Page 4. Accessed on 22 February 2024 at: <https://ndis.gov.au/media/6651/download?attachment>.

³ 53% for East Arnhem, 59% for Darwin remote. Northern Territory Quarterly Performance Dashboard 31 December 2023, NDIS. Page 3. Accessed on 22 February 2024 at: <https://ndis.gov.au/media/6651/download?attachment>.

⁴ Northern Territory Quarterly Performance Dashboard 31 December 2023, NDIS. Page 3. Accessed on 22 February 2024 at: <https://ndis.gov.au/media/6651/download?attachment>.

geographically specific, and the programs work together enabling integrated socio-legal client support.

Additional DCLS initiatives include:

- NT Older Person's Safety from Abuse initiative including the NT Older Person's Abuse Information Line
- Aged Care Financial Advocacy
- NDIS appeals advocacy, and
- Homeless Legal Outreach.

DCLS provides legal and advocacy assistance in relation to social security legal issues, credit and debt, consumer, employment, discrimination, tenancy, adult guardianship, and related matters. Staff include advocates with expertise in aged care, health specialisations, disability, community services and staff who are legally trained.

Staff involved in assisting in relation to the NDIS are involved in multiple matters, they participate in communities of practice and are involved in NDIS information dissemination and NGO disability networks, including local, NT wide and national networks. DCLS is a member of the Disability Advocacy Network of Australia ('DANA').

Advocacy and Legal Help for people with disability

Darwin Community Legal Service (DCLS) provides both legal and advocacy services across the NT for people with a disability. Existing funding for both services does not cover the needs of people with disability, especially outside of urban centres. Limited travel funding impacts on our ability to effectively support RRR participants. Our peak body, DANA has identified the following funding needs to ensure that people with disability can access advocacy across Australia:

- \$43 million for National Disability Advocacy Program (NDAP) organisations to meet existing advocacy demand until mid-2025.
- \$25 million to establish a new grant round for non-National Disability Advocacy Program (NDAP) organisations in need of urgent funds.
- **\$20 million as a dedicated funding boost for independent disability advocates facing increased operating costs in rural, remote, and very remote areas.** This proposed figure, pro-rated for 18 months until end of June 2025, should fund at least 70 new advocates working in rural, remote and very remote areas, as well as training and support needed to expand the workforce. DANA recommends this investment be used to assess demand and understand work requirements in these areas to allow for adequate rural, remote and very remote funding in the next NDAP funding cycle.⁵

In addition to advocacy funding, there is an urgent need to fund access to justice for people with disability. The NDIS has impacted the lives of many people with disability and created a need for

⁵ <https://speakupadvocacy.com.au/>

specialised legal assistance including NDIS access, planning, reviews and Administrative Appeals Tribunal assistance. Other relevant areas of law that people with a disability need legal assistance relate to NDIS service provider, employment issues (for example the employment of support workers) and consumer law. The need to fund community legal centres and Aboriginal Legal Services, to meet demand is pertinent in RRR communities to enable the provision of high-quality advice and representation for people with a disability.

Recommendations

1. NDIA to work with local clinics and remote councils to provide targeted community based, group NDIS access support.
2. NDIA to work with community representatives to identify suitable service providers.
3. Clear guidance for remote planners regarding the funding of travel for participants to access (intensive) therapies outside their remote communities
4. More oversight of NDIS providers in remote communities.
5. NDIS Quality and Safeguarding Commission to focus on support coordination providers with perceived conflicts of interests with STA and SIL providers.
6. NDIS Quality and Safeguarding Commission to focus on support coordination providers who in a short period of time start servicing a large group of participants in a particular remote community.
7. NDIA to provide direct community education and capacity building support on the NDIS to remote participants.
8. Clear information sharing pathways to be created for remote clinics, NDIS providers and the NDIA.
9. Additional funding for disability advocacy providers, as well as accessible disability legal services, including, but not limited to NDIS appeals funding.

Case studies

The following case studies highlight some of the main issues rural, regional and remote NDIS participants face in DCLS' experience.

These case studies are deidentified to preserve client privacy.

	Remote clinic worker Anna*
Brief outline of the situation	<p>Anna* is a health worker based in a clinic in a remote community in the Top End of the NT. At community education sessions delivered by DCLS disability advocates Anna expresses her concerns about the lack of communication between NDIS providers and the clinic.</p> <p>Anna manages the medication and treatment plans for several community members with psychosocial disabilities. Anna's interaction with the NDIS supports her clients access are limited, and she does not have a direct relationship with the support coordination. Anna is concerned, as she has experienced clients leaving the community for NDIS respite, without Anna's knowledge. This means that Anna has not been able to ensure that the client can access necessary medication including depot injection in their location, which poses a significant risk to her clients.</p>
Impact on the individual	Exposing clients to risks as they travel away from their primary supports without potential access to necessary medication.
Systemic issues relating to rural, regional or remote participants	<p>Lack of clear communication pathways between NDIS providers and essential health and mental health providers.</p> <p>Inconsistent and unclear information sharing arrangements between public health systems, NDIS providers and the NDIA.</p>

	Client Brian*
Brief outline of the situation	<p>Brian* lives in a remote community several hours drive from Darwin. In the wet season, his community is not accessible by road. Brian has an extensive history of hospital admissions relating to his psychosocial disability, including emergency and involuntary submissions.</p> <p>Brian is not accessing any disability supports. His home community has a CDP provider, and a remote council providing basic aged care supports. There are no disability support providers or NDIA community connectors. Knowledge of the NDIA and supports it could provide is non-existent.</p> <p>Brian has been unable to work due to his disability and prioritises income support. Brian has been unable to submit a claim for the Disability Support Pension independently. He receives support from DCLS to submit a claim for the Disability Support Pension. DCLS is able to attend his home</p>

	<p>community approximately three times a year, and it takes 8 months to provide evidence for the claim, submit and get a positive outcome.</p> <p>There is no NDIS presence in the community that Brian could relate to start understanding or considering the kind of supports an NDIS plan can provide a person with disability. There are no providers that DCLS would be able to refer Brian if he were to become an NDIS participant. Brian continues to manage his disability through the remote clinic, not accessing any capacity building or other supports.</p>
Impact on the individual	No disability supports in the community for Brian. Pattern of escalation of his mental health leading to evacuation out of the community and hospital admissions.
Systemic issues relating to rural, regional or remote participants	<p>Extensive delays in accessing appropriate income support payments, which is the priority for many remote people with disability. Without access to adequate resources and housing, the NDIS cannot be a priority.</p> <p>Communities such as the one Brian lives in need a targeted approach driven by the NDIA to establish the NDIS as an effective resource for the community. The community has several people with disability who would likely meet the NDIS access criteria. The NDIA should provide a cohesive approach to enable people with disability to start accessing the scheme.</p>

	Client Charlie*
Brief outline of the situation	<p>Charlie* is a young person with disability, living in a remote community only accessible to major cities by air. The community Charlie lives in has limited services available to Charlie. Charlie is funded in her NDIS plan to receive therapeutic supports. Due to her age, her allied health team is focused on early intervention to build Charlie's capacity and mitigate the need for future supports.</p> <p>Charlie's parents asked the NDIS remote planner to consider funding these supports. The NDIS planner did not include the necessary supports in the plan. Charlie's parents submitted an internal appeal regarding the funded supports, which was unsuccessful. Charlie's parents pursued an appeal at the Administrative Appeals Tribunal, where the requested supports were found to be reasonable and necessary and included in Charlie's NDIS plan. This process took 12 months, during which time Charlie did not receive the supports in question.</p>
Impact on the individual	Delays in the provision of capacity building supports for a young person who needs early intervention supports.

	Parental stress and risk of burn out due to the burden of appealing NDIS decisions and providing additional extensive evidence of their child's needs.
Systemic issues relating to rural, regional or remote participants	<p>This case is one of many similar cases where DCLS have supported young people in remote areas to access therapy supports in regional centres. Each time, we have supported the client at the Administrative Appeals Tribunal, in virtually the same set of circumstances, with a positive outcome, but only after months of appeals processes.</p> <p>This delay could be avoided by the NDIA formulating transparent and robust guidelines around providing funding for intensive therapy that necessitates travel, as ancillary costs of a reasonable and necessary support. Educating remote area planners to make better decisions at the planning stage.</p>

	Client Dane*
Brief outline of the situation	<p>Dane* is an NDIS participant who lives in a remote community in the Top End of the NT. This community's NDIS participants are predominantly accessing services from FIFO service providers. Dane has an intellectual disability and is supported by family members who are his carers, as well as legal guardians.</p> <p>Dane has an NDIS plan that includes funding for supports such as support coordination, community access, employment supports, capacity building supports and respite.</p> <p>Dane's guardians were approached by a support coordination provider providing FIFO services to the area and started accessing their services. Dane's support coordinator has not provided any capacity building supports helping Dane's guardians navigate the NDIS. Dane's guardians have a clear understanding of the kind of supports they know Dane wants and would benefit from and have communicated this to the support coordinator. The support coordinator however has not assisted with resolving issues with current supports or engaging new supports that fit Dane's needs.</p>
Impact on the individual	Lack of knowledge and capacity around the NDIS persisting, as the support coordinator is not delivering any capacity building to the guardians of their client.
Systemic issues relating to rural, regional or remote participants	Lack of meaningful engagement by support coordinators, especially those flying in and out of communities, to assist remote clients in understanding and navigating the NDIS.

	This creates ongoing dependence on service providers and higher risk of providers taking advantage of clients due to lack of understanding.
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If you have any questions, please contact:

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Yours Sincerely,

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Darwin Community Legal Service