Submission to the Joint Standing Committee on the National Disability Insurance Scheme Inquiry into NDIS Participant Experience in Rural, Regional and Remote Australia

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Public Health Association
AUSTRALIA

The **Public Health Association of Australia** (PHAA) is Australia's peak body on public health. We advocate for the health and well-being of all individuals in Australia.

We believe that health is a human right, a vital resource for everyday life, and a key factor in sustainability. The health status of all people is impacted by the social, commercial, cultural, political, environmental and economic determinants of health. Specific focus on these determinants is necessary to reduce the root causes of poor health and disease. These determinants underpin the strategic direction of PHAA. Our focus is not just on Australian residents and citizens, but extends to our regional neighbours. We see our well-being as connected to the global community, including those people fleeing violence and poverty, and seeking refuge and asylum in Australia.

Our mission is to promote better health outcomes through increased knowledge, better access and equity, evidence informed policy and effective population-based practice in public health.

Our vision is for a healthy population, a healthy nation and a healthy world, with all people living in an equitable society, underpinned by a well-functioning ecosystem and a healthy environment.

Traditional custodians - we acknowledge the traditional custodians of the lands on which we live and work. We pay respect to Aboriginal and Torres Strait Islander elders past, present and emerging and extend that respect to all other Aboriginal and Torres Strait Islander people.

Familycare offers a range of services to families, children and young people across the Goulburn Valley Region of Victoria. With a base in Shepparton, Familycare has offices in Cobram, Seymour and Wallan and outreach to Alexandra, Kinglake and Kilmore.

Familycare works with individuals, families and communities to increase wellbeing, build strengths and encourage optimism. Our vision is strong families and communities.

We acknowledge and pay our respects to the traditional Aboriginal owners of the land on which FamilyCare delivers services. We also acknowledge the vital role that culture plays in the development, well-being and safety of Aboriginal children.

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Introduction

PHAA and Familycare welcome the opportunity to provide input to the national consultation on *NDIS Participant Experience in Rural, Regional and Remote Australia*. This submission aims to address the Terms of Reference set by the Joint Standing Committee on the National Disability Insurance Scheme with a focus on core issues of concern for PHAA: equity, inclusion, human rights, and adequate and appropriate workforce.

Relevant PHAA policy position statements include:

- Disability and Health[1]
- Rural Health[2]

The experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews

There has been an improvement in rural, regional and remote experiences of the planning processes since the initial roll out related to improved interactions between participants and the NDIA and increased funding in packages,[3, 4] but issues and barriers persist.

Funding for travel:

A lack of funding for travel for rural, regional and remote participants persists and this impacts planning and service delivery. Socio-economic and geographic barriers compound participants' negative experiences of the NDIS planning processes. In regard to plan implementation, the financial and time burden related to transporting participants to appointments may be significant and prohibitive (for example, individual sessions requiring a round trip of hundreds of kilometers[5]), particularly in locations where therapists are unwilling, or unable, to travel to the participant, or the participant's allocated funding is inadequate to cover therapist's travel costs.[5]

Emotional toll of planning process:

Participants reporting an emotional toll and even burn out due to barriers encountered during the planning process. The challenges or inability to access supports, despite available funding, contributes to carer stress for rural families and mean that participants miss out on beneficial services.[5]

Barriers to holistic approaches in rural areas:

NDIS planning processes may hamper holistic approaches to service delivery in rural areas, or fail to account for the specific challenges faced by rural carers supporting a family member with disability. Limited discussion and negotiation time between participants and planners leads to plans that inaccurately capture the day-to-day lives of rural people with disability. As a result, support needs are not met in a way that ensures the broader family system is able to function effectively.[6]

Recommendation:

Improve NDIA and Partner in the Community engagement in rural, remote, and regional Australia to assist with all stages of the NDIS, considering rural lifestyles, relationships and geographic implications on service access and delivery, including adequate resourcing for travel.

The availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional and remote participants

The NDIS Review has noted that inexperienced NDIA staff and a workforce suffering from high turnover have had negative impacts on NDIS participants and carers.[3, 7] These limitations are particularly pronounced in rural, regional and remote Australia.

Service delivery in rural Australia:

During the roll out of the NDIS in rural Victoria and New South Wales, some rural disability service providers were indecisive about whether to become NDIS providers due to the inadequate service prices and restrictions on travel funding which was necessary to provide services to participants in rural, regional and remote communities. In Tasmania[4, 8], service coordinators have reported significant difficulties connecting NDIS participants with allied health professionals to provide services, due to workforce shortages. Support coordinators in these regions have resorted to accessing services from other Australian states via telehealth and through the fly in fly out model, although this is not considered the ideal strategy.[9]

A Case Study : Family engaging with LAC

Participant:	17yo male, still at school, lives with mother 56yo and father 76yo, both with own capacity issue struggles.
Primary diagnosis:	Intellectual disability IQ 55 and mild speech impediment, extremely naïve and easily lead.
Goals in life:	Job, driving license and living out of home. Has current NDIS package.
Family situation:	Parents receive Centrelink payments, no other income, live 30mins out of town, have one car but not enough resources to keep the car fueled, to keep their phones in credit or access to the internet.
Parents:	Dad cannot read or write and Mum can read with no comprehension and their general cognitive abilities are disorganised. They have no internet access and phone use is limited to phone calls.

The family's experiences with the administrative side of negotiating an NDIS package is complex and the challenges remain ongoing.

The first time this family engaged with their LAC it was via the telephone because they lived out of town and were unable to get into town to attend the appointment. Even though the parents did not understand what they had agreed to, a NDIS package was secured but it was inadequate for the participant's needs.

Through a family support person, a review was requested and the support person ensured that the review with the LAC was conducted in person with the mother present. During the interview, the LAC saw how the mother nodded and agreed to everything that was discussed. However, when the support person asked the mother to explain what she had agreed to, the mother replied that she had no idea what was going on. It was only then that LAC was able to understand that while the package was for the son, the mother's ability to understand and comprehend created another layer of complexity to negotiating with the family.

The result of this early interaction saw the family disengage from the NDIS process because it was too hard.

Add this to the way information is often disseminated in print and online, this family have no ability to read and comprehend the NDIS process at all.

Burden on families and carers:

As a result of the ineffectiveness of the NDIA in rural, regional and remote communities, carers and family members of people with disability are left with significant responsibilities and decisions to make. In the roll out of the NDIS, rural service providers in Victoria have reported instances in which participants were not receiving adequate supports under the NDIS, which forced carers to make the heartbreaking decision to relinquish care to a government run residential service.[4] Familial carers of children with disability have reported being left with the responsibility of negotiating and coordinating access to supports for their children due to limited insight from support agencies and inadequate response by the NDIA.[5] More recently, participants have noted that carers and family members manage the burden of NDIS bureaucracy due to participant's experiencing exhaustion from the experience.[10]

Recommendation:

Adress systemic issues affecting the capacity of the NDIS workforce and high turnover. Address the specific funding constraints impacting NDIS services in rural areas.

Participants' choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services

There continue to be significant issues with availability and accessibility of services and supports in rural, regional and remote Australia, with fewer available services, workforce shortages, limited appropriate services, long waiting times and extensive travel.[9, 11]

Inability to meet demand:

The service sector in rural areas has not expanded to meet the increased demand resulting from the NDIS.[11] Fewer services and limited appropriate services severely restrict participants' choice and control over NDIS services and supports,[10] and have resulted in a sense of uncertainty of access for participants.[10] A limited or completely absent market for NDIS services in regional and remote areas can lead to a lack of accountability for service providers, and can increase the risk of exploitation of people with disability. In particular,[12] there is a workforce shortage of allied health professionals in rural, regional and remote areas.[13-15] A lack of accessible allied health services hinders participants in achieving their goals. The federal government provides funding to strengthen the rural health workforce via the Rural Health Multidisciplinary Training program. However, specific, targeted and innovative strategies are required to build the skilled workforce required to meet the needs of NDIS participants, particularly in rural areas.

NDIS services can be subject to rules and standards that are supervised separately by both the State/Territory government and Commonwealth government. While rules can cover the same subject matter at State and Commonwealth level and be relevant to the same categories of NDIS service user, there can be significant differences in requirements for evidence, reporting and compliance monitoring.[16] This adds cost and complexity and increases resources required to meet the overlapping and duplicative compliance responsibilities, which acts as a barrier to a higher volume of services in rural areas.[16]

Need to address barriers to travel:

Travel costs in rural, remote and regional Australia use a lot more of participants' funding with health practitioners and support coordinators travelling significantly larger distances to provide supports in rural areas compared with metropolitan areas.[13] Digital health and telehealth approaches could be used to supplement in person services to increase accessibility, but building a fit for purpose rural health, social and disability workforce remains paramount.

A Case Study: Accessing activities and services

Due to financial (fuel to travel to and from town) and cognitive (time management) difficulties, the family are unable to ensure that the participant can attend his speech and OT appointments consistently. The same inconsistency of attendance relates to the participant's ability to attend school regularly.

The family does now receive 10hrs a year support coordination but to date (February 2024) have utilised 25hrs because of their inability to understand and comprehend any of the processes or concepts that relate to their responsibility. Lacking phone credit means they are unable to always ring to cancel appointments. Therefore, there is a cognitive disconnect in understanding why they are still charged for missing the scheduled appointment.

Most NDIS providers charge for a block of 2-4hrs for travel. This participant only needs someone to take him from school to his half hour appointment with a travel time of up to 15mins but the NDIS support coordinator has been unable to find someone willing to only charge for this amount of time. Given that his family is unable to afford the taxi fares and allied health professionals are not able to hold these appointments at the school, the participant often misses out. While it could be argued that the family are at fault, it is clear that NDIS providers only providing 2-4hr blocks for travel, eats into a participant's NDIS package if their travel time is less than half an hour.

One of the activities this participant does enjoy is the social trips he attends with a support worker who takes him and 3-4 other young men on day trips over the weekend. In general, this is often as simple as travelling to Melbourne, walking around for a bit (i.e. activities with no cost) and then driving back home. Given there are limited options of service providers providing group social activities and because the participant likes the support worker, there is limited opportunity to ensure that the activities received are value for money.

This participant also wishes to leave home, get a job and learn to drive.

Currently there are no options available in this area for care-supported, living out of home and this is not being considered at this stage.

To date, learning to drive is being undertaken in school, but this has been a very slow process due in part to his inability to attend school regularly. It is therefore anticipated that he will require lessons post the end of the school year. There are limited opportunities to learn to drive for people who live out of town.

The participant did want an apprenticeship to work on a farm. Instead, the school provided him with a school-based apprenticeship as a warehousing staff member in a large chain store. While he is at school, there is support in place to help him attend his workplace. These supports will no longer be available at the end of the year; he will have to find his own way to work, and he will be working in a job that he did not want to do in the first place.

It is one thing to have access to a NDIS package, but the ability to spend that funding on the needs of the participant is only possible when you have the ability to travel to the relevant appointments and activities, the capacity to organise yourself or live with someone who can help you with the organisational logistics, and access to service providers who provide quality services that are value-for-money.

It is also imperative that NDIS staff who negotiate NDIS packages for participants consider the participant's and their carer's capacity to access NDIS information in its varying forms. Families with poor access to a regular and decent income do not always have access to the internet, have the capacity to purchase the appropriate technology, nor maintain appropriate levels of credit, plus may face literacy challenges when reading either online or in paper formats.

Rural underspend:

Participants in rural, regional, and remote areas in Victoria were found to receive smaller plans on average and spend less.[17] Spending would still be lower in rural and remote areas even if plan sizes were larger for rural and remote participants due to spending barriers associated with the limited or complete absence of available and appropriate services for many rural and remote participants.

Consistent underutilisation of funding may, in turn, impact on perception of the effectiveness of supports and future budget allocation.[18, 19]

Recommendations:

Strengthen the rural health, social and disability workforce and its capacity to provide services to rural NDIS participants by delivering higher education in rural, regional and remote locations and tailored training to deliver the skilled workforce required to meet the needs of rural NDIS participants.

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

Several groups of NDIS participants have been identified as being potentially 'at-risk' of plan under-utilisation including participants living in regional and remote areas; Aboriginal and Torres Strait Islander participants; participants from culturally and linguistically diverse backgrounds; participants facing socioeconomic disadvantage, and participants with psychosocial disability or complex needs.[20] Regional and remote participants may also be Aboriginal and Torres Strait Islander participants, from other cultural or linguistic backgrounds, live in socioeconomically disadvantaged areas or have complex physical or psychosocial needs, and therefore may experience multiple and compounding barriers to plan utilisation. However, there is limited published research on the experience of culturally and linguistically diverse and Aboriginal and Torres Strait Islander participants in regional, rural and remote areas.[3]

Aboriginal and Torres Strait Islander Participants

An increase in both the proportion and number of Aboriginal and Torres Strait Islander participants in recent years is a positive step, and emphasises the need for the provision of culturally safe planning and service delivery for this growing cohort, who represent 7.8% of all participants.[21] The issues faced by non-Indigenous NDIS participants in rural and remote areas are compounded for Aboriginal and Torres Strait Islander participants who require not just appropriate services for their disability but also culturally safe services and supports.[20] A lack of cultural competence during NDIS assessment and planning processes contributes to confusion and distrust towards the scheme among Aboriginal and Torres Strait Islander participants, whilst insufficient accounting for cultural needs is a recognised barrier to plan utilisation.[22]

Communication barriers between NDIA staff and Aboriginal and Torres Strait Islander participants impact on participant understanding of the scheme, likely impacting the effectiveness of planning meetings.[22] Conversely, the involvement of family members, trusted service providers and NDIA Community Connectors, and the appropriate use of interpreters, are identified as ways to promote understanding and participant engagement in NDIS processes.[22] Research has found that despite similar plan sizes for Aboriginal and Torres Strait Islander and non-Aboriginal or Torres Strait Islander participants, there are significant inequities in spending.[17] The provision of culturally appropriate supports - including being

supported by Aboriginal and Torres Strait Islander disability workers and recognition of the role of extended family groups - facilitates better service engagement and higher plan utilisation.[20] Limited support services in regional and remote Aboriginal and Torres Strait Islander communities result in some Aboriginal and Torres Strait Islander participants experiencing displacement from their communities to access supports in other locations,[23] negatively impacting social participation and family connections. PHAA welcomes the NDIA's commitment to co-designing the First Nation's Strategy and calls for the embedding of principles of Aboriginal and Torres Strait Islander leadership; Culturally grounded approach; Respect; Benefit to community; Inclusive partnerships; and Transparency and evaluation.[24]

Culturally and Linguistically Diverse Participants:

People from culturally and linguistically diverse backgrounds already face barriers to services and supports even in metropolitan areas, and even if they are not disabled.[25] Barriers may include: lack of culturally safe service providers, language and communication barriers including variable access to interpreters, limited understanding of Australian systems contributing to challenges with self-advocacy, and experiences of discrimination.[26-28] Understandings of disability differ within and between culturally and linguistically diverse communities,[28] and may differ from concepts of disability underpinning the NDIS. Cultural expectations, including relating to the family's role in providing care rather than seeking formal supports may contrast with values emphasised in the NDIS, such as individualism and independence.[28] Some people with disability from culturally and linguistically diverse communities may experience negative attitudes or stigma around disability which may contribute to social isolation and reduced engagement with services, and there may be concerns related to using interpreters from the cultural community.[28]

These challenges may be exacerbated for people with disability from culturally and linguistically diverse communities who live in rural and remote areas, where the market for NDIS services is thin and access to interpreting services is particularly limited.

Engagement in the NDIS planning process is negatively impacted by limited English language skills for some culturally and linguistically diverse participants[20] whilst, in some instances, interpreters present in meetings speak a different dialect to the participant. Furthermore, the complexity of language used throughout the process presented a barrier to understanding for some participants.

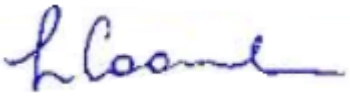
Recommendations:

Provide access to support coordination, understanding of NDIS processes, and support from disability service providers to Aboriginal and Torres Strait Islander participants and participants from culturally and linguistically diverse backgrounds.[20] Culturally appropriate services are essential. Ensure cultural safety at every level of the NDIS. Ensure translators and interpreters meet the needs of NDIS participants.

Conclusion

This submission emphasises that NDIS participants in rural, regional and remote Australia experience significant inequities in availability and access to NDIS supports compared with NDIS participants in metropolitan areas. These inequities are amplified for rural, regional, and remote Aboriginal and Torres Strait Islander and culturally and linguistically diverse NDIS participants. The inequities faced by rural, regional and remote NDIS participants exacerbates barriers to inclusion. Our submission has also emphasised the need for an adequate and appropriate workforce. The PHAA appreciates the opportunity to make this submission.

Please do not hesitate to contact me should you require additional information or have any queries in relation to this submission.



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