



people with
disabilities
western
australia

NDIS participant experience in rural, regional and remote Australia

Joint Standing Committee on the National Disability Insurance Scheme

People With Disabilities (WA) Inc.

Chair: Nihal Iscel

Chief Executive Officer: Brendan Cullinan

Report Author: Danielle Loizou-Lake

City West Lotteries House, 23/2 Delhi St, West Perth, WA 6005

Email: brendan@pwdwa.org

Tel: (08) 9420 7279

Country Callers: 1800 193 331

Website: www.pwdwa.org

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People With disabilities WA (PWdWA)

PWdWA is the lead member-based disability advocacy organisation representing the rights, needs, and equity of all Western Australians with a physical, intellectual, neurological, psychosocial, or sensory disability via individual and systemic advocacy. We provide access to information, and independent individual and systemic advocacy with a focus on those who are most vulnerable.

PWdWA is run by and for people with disabilities and aims to advocate for the rights and empower the voices of all people with disabilities in Western Australia.

1. Executive Summary

This report has been produced by advocacy organisation People with Disabilities Western Australia. The purpose of this report is to provide the Joint Standing Committee, insight into the Western Australian lived experience of the National Disability Insurance Scheme (NDIS) in rural, regional and remote parts of the state. The report responds to the terms of reference by interviewing people with disability living in rural, regional and remote parts of Western Australia. The findings with recommendations are detailed in this report.

2. Acknowledgments

PWdWA would like to acknowledge the contribution of the 19 people who were interviewed to provide the contents of this submission and their enduring spiriting toward improving the NDIS for all Western Australians.

PWdWA also acknowledges the cooperation of the following organisations:

- Advocacy WA
- Explorability
- Great Southern Community Legal Services

3. Summary of recommendations

The full recommendations based on the findings from this consultation are presented on page 16. Below is a high-level summary of the recommendation areas.

1. NDIS Application process support
2. Improve NDIA communication and follow-up
3. Improve mainstream service interface
4. Develop NDIS regional context and support
5. Address availability, quality and cost of disability services
6. NDIA to become a more culturally appropriate agency
7. Fairness in Administrative Appeals Tribunal (AAT)

4. Introduction

In Western Australia over 411,500 people live with disability, this is around 15 percent of the WA population (1). Seventy nine percent of the WA population lives in the Perth area leaving the remainder of the state sparsely populated. Western Australia is Australia's largest state, with a total land area of 2,527,013 square kilometres (2). This makes Western Australia's disability ecosystem different from any other state in Australia. People living in rural and regional towns may be hundreds or thousands of kilometres from Perth where they need to access specialist disability services. Eighty-nine thousand Western Australians identified as being of Aboriginal and/or Torres Strait Islander, with over 95% of this group identifying as Aboriginal (2). A large proportion of the Western Australia Aboriginal community live outside the metropolitan area. In the local government area of Derby-West Kimberley, Aboriginal people make up 60.3% of the population and in Broome 28.6% of the population (2). In these areas the NDIS and disability services should be culturally appropriate and fit for purpose.

5. Problem Statement

This report highlights where the national roll out of the NDIS has met the needs of people living in rural, regional and remote areas and where there remain opportunities to rethink the current approach. With Western Australia's unique geography, people in rural, regional and remote communities have limited choice and variable quality of providers. Aboriginal Western Australians have a right to continue their connection to country and remain living on their ancestral lands. However, despite the NDIS's Rural and Remote Strategy 2016-2019, Aboriginal people do not report easy access to the National Disability Insurance Agency (NDIA). They reported they often cannot access supports where they live and report no known efforts by the NDIS to support or strengthen the capacity of their local community (3).

6. Methodology

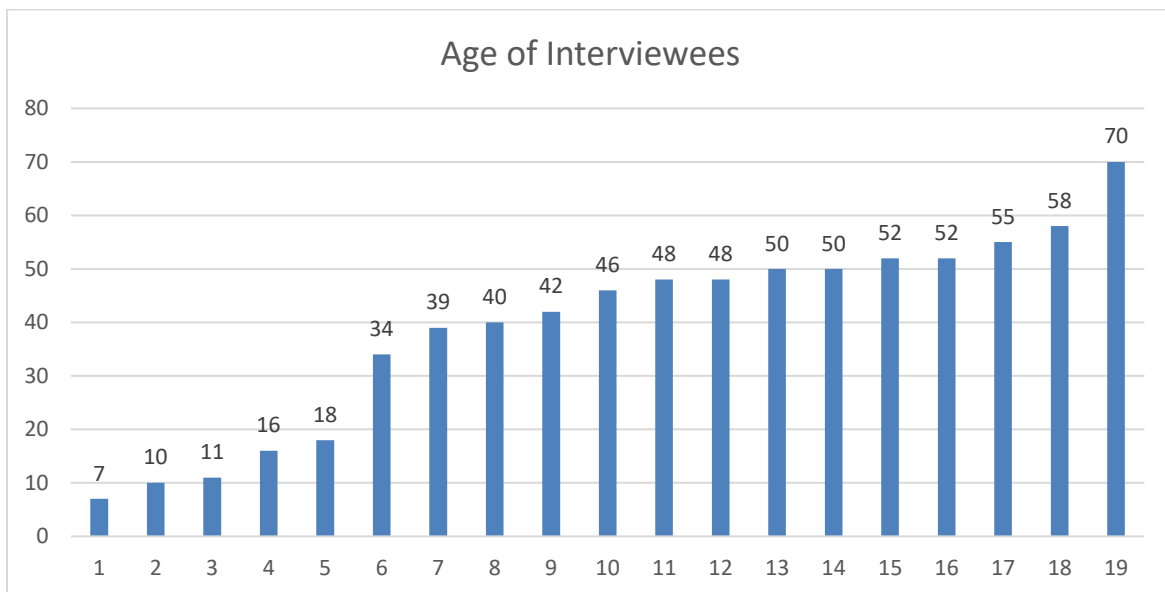
PWdWA invited rural, regional and remote people with disability to participate in an individual meeting or focus group. Overall, 19 Western Australians with a range of disabilities participated from across the state (see table 2). Those who participated received a \$50 gift card as recognition of the time they gave to contribute to this submission. Thirteen in-depth interviews of 45 minutes to 1 hour were conducted either face to face, via video conference or phone depending on the person's

preference and if they had access to internet. One group interview was conducted for six people from the very remote community of Balgo.

Demographic

Of the 19 people that participated in this consultation:

- 12 identified as male and 7 as female
- Ages ranged from 7 to 70 (see graph 1)
- 8 people identified as Aboriginal



Graph 1- Age range of consultation participants

Geographic location

People were interviewed from across the state of Western Australia, including the Kimberly (10), Pilbara (1), Mid-West (1), Wheatbelt (1), Goldfields (1), South-West (3) and Great Southern (2).



Image 1- Map of consultation participants

Disability type

Disabilities identified by participants	Self-reported*
Physical	6
Deaf/ Hard of Hearing	1
Blind/Low vision	2
Cognitive	6
Neurodevelopmental	3
Psychosocial	4
Intellectual and Developmental	2

Table 2 – Disability types reported*

**Some consultation participants reported multiple disabilities.*

7. Findings

The findings are organised as per the Joint Standing Committee Terms of Reference inquiring into the implementation, performance and governance of the NDIS. The consultation findings below report on the Western Australian's participants experience of the NDIS in rural, regional and remote Western Australia.

7.1 Participant experience of stages of the NDIS

Application to become a participant: Some people transferred from the existing state-based system to the NDIA, they said this process was simple. Some adults found it very difficult and overwhelming, while others who were supported by the health system while in hospital found it much easier. Parents required to apply for their child's access found the process emotionally sensitive and challenging, especially while dealing with their child's diagnosis. Some had help from professionals like speech pathologists, while most others felt overwhelmed and isolated without proper guidance.

Plan design and implementing plans: The majority of people stated they would prefer face to face meetings for better communication and understanding. All nine Aboriginal people interviewed said they would like to talk with a person face to face. Some people stated the planners were distant and didn't record their personal information correctly. Some parents of child participants reported positive experiences with planners who listened to their child's needs and goals while others felt like their child was treated as just a number, lacking empathy from NDIA planners. When plans were received several respondents mentioned difficulties in understanding their plans and how to implement them. Some also faced challenges in implementing the plan due to limited provider options or inadequate support to engage providers.

Plans automatically extending or 'rolling over': Many people stated their NDIS plans have auto extended or 'rolled over' for many years without having the opportunity for a review. This was particularly evident in Aboriginal communities where seven out of eight people interviewed said their plans had rolled over for more than four years without hearing from a NDIA representative. People suggested they would like to be

contacted to ask if they want their plan to roll over or if they need to review their supports.

Communication issues and lack of follow-up: Many participants expressed frustration with communication gaps from the NDIA, such as not receiving timely updates or follow-ups on their requests or changes errors in the plan, management types or change in circumstances. Most participants reported their frustration with not being able to contact a person in the NDIS that could assist with a request. It was commonly heard that after a planning meeting participants and parents couldn't contact the person they just had the meeting with resulting in time consuming and frustrating calls to the NDIS 1800 number and email to enquiries@ndis.gov.au that took months to be responded to. Participants and parents who did not have access to a support coordinator expressed significant feelings of being unsupported and overwhelmed. Shockingly three families interviewed reported psychological breakdown resulting in medical support for the parent attributed to the NDIS process. Respondents suggested that a NDIA officer or team be allocated to participants' case, particularly in the circumstance of planning meetings that are not completed and need follow up. It was repeatedly suggested that the same NDIA officer or team should be required to follow up the participant or family, until the review is fully completed and the participant is able to implement.

Regional context and support: There were concerns about planners from major cities lacking understanding of regional challenges and needs. Participants suggested better training for NDIA staff or having equipped local offices, to improve support for individuals living with disabilities in regional areas. Many participants and families suggested better linkages between health, education systems, and the NDIA, parents in particular felt an overwhelming responsibility to be the link between these services that often worked in isolation resulting in gaps. For example, school and NDIS behaviour support, and NDIS therapists not being able to attend schools. Some people stated the previous Western Australian state based Local Area Coordinator models was much more effective at linkages and support for families. One mother commented that the NDIS experience 'is very lonely' and another stated they are 'constantly in fear of funding changes'.

Legal challenges and appeals: Through the plan review process some people experienced legal challenges with the AAT. Some reported feeling coerced or bullied by NDIA lawyers during this process. They emphasised the need for fair legal representation, stating if the NDIA had lawyers for the AAT, the participant should also have funded access to lawyers.

Case example: Parents' experience of NDIS stages (Bunbury)

**names changed*

Background:

The Johnson family* automatically met NDIS access for their teenage daughter, Emily*, who has Downs Syndrome when transferring from the WA state-based Disability Service Commission. Their experience with the NDIA was marred by bureaucratic challenges and significant emotional strain.

First planning meeting:

The initial meeting left the parents feeling like *'Emily was just a number from day 1'*. The process lacking personalisation and empathy. They struggled with understanding the 'evidence requirements' and felt lost in navigating the complex process.

Plan received and review meetings:

Constant funding disapprovals and impersonal plan review meetings added to the family's stress. They reported feeling like failures as parents and faced emotional distress due to the NDIS rigid criteria for specific evidence and technical language. *'We are two ordinary working parents, that couldn't understand the language and evidence that was needed'*. The family progressed to the AAT to have Emily's funding issue addressed and their request for the funding change was accepted by the NDIA lawyers before AAT hearing. The family felt that the NDIS process was unnecessarily burdensome and psychologically traumatic.

Communication with NDIA:

Communication with NDIA was unresponsive and often frustrating. Updates were not made, and issues were *'fobbed off'*, leaving the family feeling unsupported.

Improvement suggestions:

The family highlighted the need for more empathetic, professional and personalised communication; NDIS staff being better trained to understand developmental life stages of children with disability; NDIS providing a case officer to complete or see through a matter (e.g. a plan review); and better disability regional planning and a deeper understanding of families' challenges in the regions. They also emphasised the importance of access to advocacy services, support coordination and plain English communication from the NDIA.

7.2 Communication and performance of the NDIA

Availability

- Many expressed confusion about the availability of local NDIA offices. For example, an individual mentioned not knowing if there is an officer or Partner in Community office in Bunbury, highlighting the lack of clear information on local service points. People in remote communities did not know who to talk to about getting disability supports. In larger towns such as Broome and Derby the NDIA offices are co-located with Centrelink, with many Aboriginal people reported having 'bad experiences' with Centrelink and won't go into the office.
- Several participants mentioned difficulties in accessing direct communication channels with the NDIA, such as face-to-face meetings or contact numbers to reach specific personnel. This limited availability hindered effective interaction and resolving plan issues.

Responsiveness

- There were complaints about the NDIA's poor responsiveness and long waiting times to a request, particularly for change to a plan or assistive technology. For example, many individuals mentioned that requests logged by phone to the 1800 number or to the enquiries@ndis.gov.au were not addressed for months. Some participants and families reported waiting over six months to hear from the NDIA about important requests which is not in line with the NDIS Participant Service Guarantees (4).

- Many expressed a desire for more accountable communication systems from the NDIA, where queries are efficiently handled, and follow-ups are conducted in a timely manner. Many people report the NDIA is similar to Centrelink with a feeling you are being ‘fobbed off’ and that it’s unlikely they are going to help with their enquiry.

Consistency and effectiveness

- Many individuals highlighted inconsistent experiences with NDIA staff, such as not speaking to the same person twice or encountering different people each time they contacted the agency, receiving conflicting information about their issue, and when it may be resolved.
- Concerns were raised about inaccurate documentation and incorrect personal information being recorded by the NDIA, leading to confusion and delays in accessing supports.
- Participants reported spending significant time and effort navigating NDIA systems and administrative functions instead of focusing on their goals and priorities.

Case example: Communication Challenges in Change of Circumstance (Boyanup)

**name changed*

Background:

Sally* underwent a significant change in circumstances due to a second leg amputation, requiring a Change of Circumstance (CoC) with the NDIS.

CoC Process:

The CoC was initiated with the help of her Occupational Therapist (OT) in August 2023. Sally engaged in a planning review over the phone with the NDIA but was advised to come back with more specific evidence. Reports were submitted in September 2023, but there was no response from the NDIA for months. Sally was not able to contact the planner and felt like she was back at ‘step 1’. Sally made multiple attempts to follow up the NDIA via email and 1800 phone number. In

January 2024 Sally visited the Bunbury NDIA office in person and asked them to follow up her review. A response came from the NDIA in February 2024 with a planner (six months from the initial meeting), calling Sally suggesting her plan should 'roll over'. Sally stated she was '*overwhelmed and exhausted, trying to adjust to life as a double amputee*', she accepted the roll over. However, her significant change in disability needs still has not been met. Sally does not have the wheelchair or mobility scooter she requested in her change of circumstance. Sally felt the planner who called her from Melbourne lacked context about living with a disability in the South West of WA and seemed uninterested in her individual circumstances.

Suggestions for improvement:

Sally suggested the following would have helped her.

- A follow-up system after pausing or abandoning the planning meeting to ensure a participant doesn't fall through the gap leaving their issue unresolved.
- Improve response times to CoC requests and requests for Assistive Technology (AT).
- Provide better training and understanding for NDIA staff regarding regional disability experiences or develop local offices for more local, personalised support.

7.3 Choice and control over NDIS services

Availability of services

- In most regional hubs like Bunbury, Albany and Broome participants can access most therapy supports, however due to limited providers participants reported a waitlist ranging from 3 – 18 months. For specialised services like prosthetics and customised wheelchairs people are required to travel to Perth.
- However, in remote areas and communities, access to therapists and support workers is limited to not available. For example, therapists travel 220kms from Broome to Derby requiring significant travel and expense to the participant's funding. In a remote community such as Balgo there are almost no supports

available. Some local people have been given basic training to deliver daily living supports, however participants report issues with them being unreliable. There are no therapists available in Balgo and many other remote Western Australian communities.

- In rural and regional towns most people reported they can get the equipment they need. Most regional hubs have small aids and equipment stores for general needs. Other more specific equipment was transported from Perth. The challenge was when people needed to be measured or trial equipment that was only available in Perth, that they were required to travel. For some people the costs associated with travel were prohibitive to them getting the equipment they require.
- In most regional hubs people reported they were able to get the trades to do home modifications. However, the delays in getting home modification were often reported as NDIA administrative delays to requests.
- In remote towns communities where housing was owned and managed by Department of Communities (DoC), people reported not having suitable accessible accommodation. Better interface between NDIA and DoC was noted to be able to progress with necessary home modification.

Accessibility of services

- Some individuals reported issues with the accessibility of services due to long wait times for equipment, and difficulties in finding experienced therapists or support workers in their area.
- Children and parents in regional areas face challenges in accessing recreational and inclusive programs for their children, leading to isolation and limited opportunities for social engagement.
- In remote Indigenous communities, there's a need for culturally sensitive and community-focused approaches, including dedicated local support workers, better governance, and improved NDIS understanding.

Cost of services

- The cost of services varies widely, with some areas experiencing inflated prices due to limited providers and high demand.
- People reported therapists' fees have significantly increased under the NDIS, making it challenging for families to afford ongoing therapies, especially in regional or remote locations.
- The cost of respite or short-term accommodation in the remote town of Broome was quoted to a participant as \$13,051.01 for one week.
- The cost of visiting therapy supports to remote communities was seen as exorbitant and beyond what participants plan could accommodate (see case example).

Durability of services

- Quality and consistency of support workers are major concerns, with reports of variable quality, lack of qualifications, and high turnover rates.
- Some individuals had positive experiences with agencies that allow them to engage in 'shared management' where the participant can be involved in interviewing and engaging their support workers.
- People express a desire for more control over their funding, including the ability to hire independent local support workers in remote areas.
- Some people suggested the NDIA should provide access to subsidised professional development opportunities for support workers.

Case example: Cost of services in very remote aboriginal community of Balgo WA

In Balgo, five of the people interviewed required a Functional Capacity Assessment (FCA) for their NDIS plans to better reflect their disability supports needs. The support coordinator spent a lot of time sourcing quotes and the following two were received:

- Provider out of Darwin: \$6,000 per FCA
- Provider out of Broome \$4,100 per FCA

A participant in Balgo required ongoing physiotherapy, the following quote of \$26,889.66 was provided for 12 months:

- Fortnightly telehealth appointments: 26 hours direct
- Quarterly face to face appointments: 4 hours direct
- Indirect travel time (5 hours per trip): 20 hours indirect
- 1 hour per month indirect clinical time for monthly correspondence, resources, home program, liaison with medical team: 12 hours indirect
- Non-labour cost: \$6,000 (\$1500 per trip)

62 hours at very remote rate \$336.93 per hour = \$20,889.66 + \$6000 non labour.

Total: \$26,889.66 per annum

7.4 Particular experience of Aboriginal and Torres Strait Islander participants

Of the eight Aboriginal people interviewed with their support person, they reported several challenges and issues with the NDIS specific to their cultural and community contexts:

Limited understanding of NDIS: Some individuals rely on friends or support coordinators to navigate the NDIS process because they themselves don't fully understand how it works. They don't want to have the 'shame' of making the wrong decision so are particularly vulnerable to what people tell them to do. For example, interviewees reported unscrupulous providers of disability support exploiting Aboriginal people, by taking their funding and either not delivering support or providing sub-standard care.

Communication barriers: Language and communication barriers result in NDIA communications during phone calls often not being understood. Many participants have expressed the need for face-to-face meetings instead of phone meetings, as they find it hard to understand over the phone and prefer personal interactions. Information sent by NDIA is often posted, many Aboriginal people interviewed in regional and remote areas said they cannot read, highlighting the need for alternative communication methods.

Challenges with support: It's challenging for people in remote communities to access support workers and therapists. In regional hubs such as Broome and Geraldton better access to support workers and therapist was reported. Some service providers lack trust within the community, leading to low participation and inefficiencies in service delivery.

Cultural sensitivity: There's a need for NDIA officers who understand the local context and culture to provide more effective and culturally sensitive support. NDIA offices being co-located with Centrelink was repeatedly noted as not appropriate, intimidating and a barrier to accessing the NDIS. People asked for a relationship-based approach where local people with local knowledge can gain employment with the NDIA and support their community to understand it better. NDIA offices, staff and resources should reflect Aboriginal people. All Aboriginal people interviewed said they wanted to be more involved and to understand their NDIS better.

Financial abuse and cultural sharing: There are concerns about financial abuse, especially regarding NDIS transport funding being misused or taken by other family members.

8. Recommendations

Based on the consultation findings regarding the participant experience in rural, regional, and remote Western Australia under the NDIS, the following recommendations are proposed:

8.1 Application process support

- Provide appropriate support and guidance for people and families applying for access.
- Simplify the application process for people living in regional and remote communities.

8.2 Improve NDIA communication and follow-up

- Prioritise face-to-face meetings for better communication and understanding, particularly for Aboriginal participants.
- Ensure planners record personal information accurately and demonstrate empathy towards participants' needs and goals.
- Establish a system to contact participants for plan reviews before auto-extending plans.
- Improve communication channels and responsiveness by assigning dedicated NDIA officers or teams to follow up on unresolved issues.

8.3 Improve mainstream service interface

- Strengthen linkages between rural, regional and remote health, education justice systems and the NDIA, to reduce gaps in support, especially for children and Aboriginal participants.

8.4 Develop NDIS regional context and support

- Employ and develop local NDIS officers that understand the local context.
- Provide better training for NDIA staff on regional challenges and needs.
- Ensure local NDIS offices are culturally appropriate, particularly in the Kimberly and Pilbara regions.
- Do not co-locate the NDIA with Centrelink offices.

8.5 Address availability, quality and cost of disability services

- Address long wait times for NDIS enquires for equipment and changes to plans.
- Improve accessibility to therapists and support workers in all regional and remote areas, considering the specific needs of Aboriginal communities.
- Develop the quality of support workers and reduce turnover rates through sector support and professional development opportunities.
- Provide opportunities to empower participants to have more control over their funding and support choices, including the ability to hire independent support workers.
- Address cost barriers and inflated prices in very remote areas.
- Address unscrupulous providers exploiting vulnerable participants.

8.6 NDIA to become a more culturally appropriate agency

- Enhance cultural sensitivity and understanding within the NDIA, including employing local staff with local knowledge.
- Develop alternative communication methods and provide face-to-face interactions to overcome language barriers and improve understanding.

8.7 Fairness in Administrative Appeals Tribunal (AAT)

- Ensure fair legal representation for participants during the AAT process, including access to funded lawyers.

Conclusion

The results of this consultation suggest the need for a more integrated and responsive approach in rural, regional, and remote Western Australia. The NDIA should give attention to improving communication gaps, developing agency understanding of regional markets and enhancing cultural sensitivity. NDIS access and implementation should be better integrated with health, education and justice systems to prevent people falling through the gaps. Importantly for the NDIS to develop in the regions, individuals should be supported to develop their capacity to use the scheme, prioritising participant involvement and empowerment, however this must be done at a local level using a relationship-based approach. Giving attention to these recommendations will enhance the overall participant experience and outcomes under the National Disability Insurance Scheme.

9. Word List

Accessible: refers to environments, resources, or services that are designed or modified to be usable by people with disabilities.

AAT: Administrative Appeals Tribunal

Carer: Friends or family who support the person with disability. Carers are people who provide support that is unpaid and not part of a paid work or community work arrangement.

Disability needs: assistance, equipment and adjustments to help a person with disability in their daily living and in their community.

Disability: This paper speaks to the social model of disability.

DoC: Department of Communities Western Australia

Inclusive: people with disabilities are fully integrated and actively participate in all aspects of society without barriers.

NDIA: National Disability Insurance Agency

NDIS: National Disability Insurance Scheme

PWdWA: Western Australian disability advocacy organisation People with Disabilities WA

Support Person: either a Carer or Support Worker

Support Worker: A person employed or otherwise engaged to provide disability supports and services for people with disability.

Therapist: referring to Occupational Therapist, Speech Pathologist, Physiotherapist, Podiatrist and Psychologist.

10. References

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