

Women With Disabilities Australia (WWDA)

WOMEN WITH DISABILITIES AUSTRALIA (WWDA)

Response to the Inquiry into NDIS Participant Experience in Rural, Regional and Remote Australia

Joint Standing Committee on the National Disability Insurance Scheme

February 2024

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ABOUT WOMEN WITH DISABILITIES AUSTRALIA (WWDA)

Women With Disabilities Australia (WWDA) Inc is the national Disabled People's Organisation (**DPO**) and National Women's Alliance (**NWA**) for women, girls, feminine identifying, and nonbinary people with disability in Australia. As a DPO and an NWA, WWDA is governed, run, and staffed by and for women, girls, feminine identifying and non-binary people with disability.

WWDA uses the term 'women and girls with disability', on the understanding that this term is inclusive and supportive of, women and girls with disability along with feminine identifying and non-binary people with disability in Australia.

WWDA represents more than 2 million women and girls with disability in Australia, has affiliate organisations and networks of women with disability in most States and Territories, and is recognised nationally and internationally for our leadership in advancing the rights and freedoms of all women and girls with disability. Our organisation operates as a transnational human rights organisation - meaning that our work, and the impact of our work, extends much further than Australia. WWDA's work is grounded in a human-rights based framework which links gender and disability issues to a full range of civil, political, economic, social, and cultural rights. All WWDA's work is based on co-design with and participation of our members. WWDA projects are all designed, governed, and implemented by women and girls with disability.

Disabled People's Organisations (**DPOs**), also referred to as Organisations of Persons with Disabilities (**OPDs**) are recognised around the world, and in international human rights law, as selfdetermining organisations led by, controlled by, and constituted of, people with disability. DPOs/OPDs are organisations of people with disability, as opposed to organisations which may represent people with disability. The United Nations Committee on the Rights of Persons with Disabilities has clarified that States should give priority to the views of DPOs/OPDs when addressing issues related to people with disability. The Committee has further clarified that States should prioritise resources to organisations of people with disability that focus primarily on advocacy for disability rights and, adopt an enabling policy framework favourable to their establishment and sustained operation.¹

Introduction

Women With Disabilities Australia (**WWDA**) welcomes the opportunity to respond to the Inquiry into the National Disability Insurance Scheme Participant Experience in Rural, Regional and Remote Australia and commends the Australian Government on its commitment to improving participant experiences of the National Disability Insurance Scheme (**NDIS**). As the Committee is aware, the experiences of participants in rural, regional, and remote areas are significantly impacted by issues relating to the availability, responsiveness, consistency, and effectiveness of both the NDIS and providers in the market.

For participants of the NDIS, access to quality supports and services underpins the realisation of several fundamental human rights, including the right to full and effective participation and inclusion in the community, as set out in Article 19 of the Convention on the Rights of Persons with Disabilities (**CRPD**). Article 9 of the CRPD also provides for the right of people with disabilities to have access, on an equal basis with others, to the physical environment, transportation, information and communications, and other facilities and services - both in urban and in rural areas.

The NDIS has a critical role in providing funded, individualised support and services to people with disabilities across Australia. The NDIS aims to enhance quality of life, independence, and access to community – yet it is failing distinct cohorts of people, including those living in rural, regional, and remote areas. Geographical barriers, thin markets and a lack of infrastructure often result in limited access to essential services and support, posing significant challenges in relation to the availability, accessibility, diversity, quality, and safety of supports and services.

What we have heard from women and girls with disabilities

WWDA held a series of consultations with women and girls with disabilities living in rural, regional and remote Australia over recent years to inform our response to government inquiries and reviews, including the Independent Review of the NDIS (2023), and the Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability (2023). We also conducted social media consultation for the purposes of this submission.

This is what we heard.

Barriers accessing NDIS and supports

There are persistent barriers for people with disability applying, accessing, and participating in the NDIS within rural, regional, and remote areas. Some of these barriers include:

- □ High cost of obtaining reports to access the NDIS.
- Long wait times for diagnostic services (pre-access to the NDIS) and service providers (post-NDIS plan).
- □ Lack of choice and control in supports and services due to thin markets.
- □ Negative interactions with NDIS and NDIA staff, including communication difficulties.
- □ Service systems not interacting with each other, resulting in significant unmet need and inaccessible mainstream services.

- □ Lack of information available about how to engage with the NDIS and what supports and services can be funded.
- □ Inadequate infrastructure (such as accessible transport and NDIS offices) which limits people's access to NDIS personnel.
- Experiences of harm, discrimination and marginalisation when engaging with services and NDIS personnel.

We also heard participants are expected to use their NDIS funding for support so they can access mainstream services, rather than mainstream services and the community being accessible. Sometimes, this is also a barrier to plan utilisation. For those people with disability who don't have NDIS funding this means they are not able to access mainstream services unless they self-fund the supports to enable the access.

I have a physical disability and require wheelchair accessible transport and building access. I have the funding for community participation; however, I reside in a rural town (town with population of 11000), there are very few activities where there are accessible buildings and events. The majority of local businesses are not accessible, this includes clothing shops, retails, restaurants and cafes. Because of this and the limited places I can access, I do not use the majority of my community participation funding.

NDIS participant, WWDA consultation

It's definitely an issue accessing qualified services like OTs, speech therapists outside regional areas. They spend long amounts of time travelling from home base to communities, which is paid for from participant plans.

- NDIS participant, WWDA consultation

Thin markets in regional, rural, and remote locations significantly impact participant choice and control in relation to NDIS services and supports including advocacy. When appropriate supports and services are available, they are generally more expensive due of lack of market competition and/or the increased cost to providing services in remote, rural and regional areas.

In rural areas, there are very limited NDIS providers, many other businesses do provide services and products that can be used by those with a disability, however unless you are selfmanaged you are restricted to only being able to access registered providers, which results in unavailability of that service or product.

- NDIS participant, WWDA consultation

I have had a great deal of difficulty finding therapists and support workers that understand mine and my kids' disabilities. We have been on waitlists and are constantly losing supports. There is a shortage of skilled support workers too. I don't know if our issues have a lot to do with living in a regional city though. I think many people are having the same issues all around Australia.

- NDIS participant and family member, WWDA consultation

I live in regional WA. We don't have any advocacy here. It is pretty hard for people to get help.... It's hard for parents and support workers and support coordinators to find what they need because they haven't got anyone to fight for them. It's really hard.

NDIS participant

The Joint Standing Committee on the NDIS (2022) proposed solutions to improve access to services in these areas, including strengthening local capacity of rural and remote communities and collaborating with other service systems to identify and understand unique service demands and gaps within individual communities. WWDA supports these proposed solutions.

Impact on support during climate disaster or extreme weather

During times of climate emergency or extreme weather events, people with disability living in rural, regional and remote areas are more likely to be impacted, and to experience additional barriers to support and basic provisions.

Down where we [were]... when the weather got rough, we had a creek that used to flood the road. You couldn't get out for a couple of days. That happened many times of the year. It was hard to get carers to come down to that place. Then there's days when we couldn't get out. Bread, milk, groceries, our carers couldn't get in. Our phone service was almost non-existent. Internet was almost non-existent.

- Carer and partner of participant, WWDA consultation for NDIS Review

Marginalised cohorts

There are specific barriers to accessing and receiving NDIS supports for people with disability who experience multiple points of marginalisation. These barriers are exacerbated where people's autonomy and choice in services are restricted. For example, we heard that some LGBTQIA+ participants had faced fear, discrimination, and harm when engaging with some faith-based organisations. Further, when services lack adequate resources and employ staff with insufficient experience and qualifications, there is increased risk to the safety and well-being of individuals the services support. This risk is significantly higher for groups of people with disability already at a higher risk of experiencing discrimination, violence, harm, or exploitation within service settings, such as women and girls with disability, First Nations people, and people from cultural and linguistically diverse backgrounds.

Barriers for families of Australian Defence Force personnel

Through our consultations, we have identified specific issues affecting families of Australian Defence Force (ADF) personnel. The mobile nature of ADF work creates significant barriers to service access for people with disabilities. Due to frequent relocations, individuals are often placed at the end of waitlists in their new area, leading to long waiting times (in some cases over 18 months) for specialist services. When they do finally get to see the specialist, it is often only for a few sessions before being relocated and then having to join waitlists on their new area. This issue also affects a person's ability to submit quality reports to support plan reviews with the NDIS, which then impacts their funding and continued access to the NDIS. This is particularly problematic at critical transition points, such as moving from the early childhood component of the NDIS to the broader scheme.

Recommendations

Recommendation 1: The NDIA must develop a comprehensive NDIS Gender Strategy in consultation with women and girls with disability, and their representative organisations to ensure equity within the Scheme. This strategy must address:

- □ An equitable approach to accessing the NDIS which addresses systemic gender inequality across the service systems and how they interact with NDIS access decisions.
- □ The collection and public reporting of data disaggregated by gender, disability and other attributes (such as location) across all phases of interaction with the NDIS.
- Needs and supports specific to the lives of women with disability including how caring and parenting responsibilities, as well as where participants live (remote, regional, rural) should be considered in relation to the NDIS plan, as well as access to supports relating to reproductive and sexual health.
- □ Pro-active measures to ensure women and girls with disability do not experience harm within support and service settings.

Recommendation 2: The Australian Government/NDIS must fund easily accessible emergency funding packages for people with disability during times of crisis. This includes people living in rural, regional and remote areas where a higher risk of natural/climate disaster exists, as well as for other crises including experiences of gender-based violence. For NDIS participants, the NDIS must allow for the flexible use of their funds during crisis and/or allow for the inclusion of emergency funding in a person's NDIS plan.

Recommendation 3: The NDIA must collect and report on data that is broken down by participant characteristics at all points of interaction with the NDIS. This will assist with understanding and addressing unmet need, including for women and girls in rural, regional and remote areas, and other cohorts.

[For example, the NDIS Quarterly Reports provide data on participant characteristics, but genderrelated data is reported only in relation to access and participation. The Reports also provide the number of complaints and incidents reported, but no information on the participant characteristics associated with that data. Yet, participants who experience overlapping forms of disadvantage are at the greatest risk of harm within service settings. Improving data collection on intersectional identities is one of the recommendations of the Royal Commission, with disaggregated complaints and reporting data addressed at Recommendation 10.26.]

Recommendation 4: The NDIA should develop specific strategies to support serving Australian Defence Force family members to access timely and consistent services and supports regardless of where they are located in Australia. This should include:

- □ Consultation and co-design with Defence Force families, and service providers.
- □ The development of innovative responses in the market to limit the disruption to participant/provider relationships as families relocate.
- □ Consideration of the impact of rules and policies such as the removal of access to the NDIS for participants who live outside of Australia because of service in the ADF.

Recommendation 5: The Australian Government should review The NDIS Applied Principles and Tables of Supports to address inadequate implementation, resolve inconsistencies in approaches from and interactions between service systems, and improve accessibility of mainstream services including in remote, rural and regional areas.

¹ Interim Report - Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

² Fifth Progress Report - Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

³ Final Report Vol 9, First Nations People with Disability, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

⁴ Final Report Vol 10, Disability Services, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

⁵ Women With Disabilities Australia Review of the Applied Principles and Tables of Supports (NDIS Review submission) August 2023.

⁶ Women With Disabilities Australia Submission to the NDIS Review Transcripts of Nine Individual Interviews conducted with women, girls, feminine-identifying and non-binary persons with disability, July – August 2023

⁷ Women with Disabilities ACT and Advocacy for Inclusion NDIS Review Submission Joint survey report September 2023. 8 Joint Standing Committee on the National Disability Insurance Scheme - General Issues Report - Work of the Committee in the 46th Parliament. 9 Joint Standing Committee on the National Disability Insurance Scheme - General Issues Report (2021).

¹⁰ United Nations Committee on the Rights of Persons with Disabilities Concluding observations on the combined second and third periodic reports of Australia, 2019.