NDIS participant experience in rural, regional and remote Australia

Introduction

The Australian Psychosocial Disability Collective (APDC) welcomes the opportunity to make a submission to the Joint Standing Committee's Inquiry into the NDIS participant experience in rural, regional, and remote Australia.

APDC is a group of NDIS participants with a Psychosocial Disability focused on giving voice to a participant perspective on NDIS policy and practice as it relates to the experiences and needs of people with a psychosocial disability.

Members of the APDC are currently based across Victoria with many of our members living in rural and regional locations. As a collective we embody the catch cry of 'nothing about us without us' and bring the direct experience and insights of NDIS participants living in rural and regional communities to our advocacy.

Our Submission to the Joint Standing Committee has been written in the wake of the release of the NDIS Independent Review Report and its recommendations; however, many of the issues that we share and comment on are long standing matters of concern for NDIS participants living in rural, regional, and remote settings.

The APDC would like to highlight that many of the recommendations of the NDIS Review will only continue to exacerbate the difficulties faced by NDIS participants in rural, regional, and remote areas.

1. Housing

A high proportion of NDIS participants with a psychosocial disability (83%) rely on the Disability Support Pension for income support and have low incomes¹. Rural and regional areas can provide lower cost housing, but the gentrification of rural and regional areas over the last 20 years has pushed up the housing costs for people with a disability living in these communities.²

¹ https://www.afdo.org.au/about-australians-with-disability/ndis-participants-employment/ Accessed 20/02/2024

² https://www.rba.gov.au/publications/bulletin/2023/jun/new-insights-into-the-rental-market.html Accessed 20/02/2024.

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There is a lack of affordable suitable housing for people with disabilities and NDIS participants. Currently 94 % of NDIS participants do not receive NDIS housing funding (SDA, SIL or ILO)³

The current affordable housing and cost of living crises have complicated issues further leaving many people in limbo with no support to find alternative safe, secure, and affordable housing options, with NDIS participants finding themselves stuck between a rock and a hard place.

It would be of huge benefit if housing for people with disability was looked at from a broader perspective, and a Disability Housing policy would be a step in the right direction. In some instances, NDIS participants are told by Planners, LACs, or Support Coordinators that they need to move closer to regional cities where they might have more options in finding support. However, they are then given no financial support in the form of subsidised Public Housing or increased Rent Assistance to enable them to move to an area where there are more NDIS services.

The recommendations from the NDIS Review final report, if approved by government, will make NDIS funded housing solutions even less accessible to people with psychosocial disability, as the Early Intervention pathway does not appear to include Home and Living solutions.⁴

If adopted this policy will disproportionately impact those living in regional, rural and remote areas where housing options are already limited and there are high rates of institutionalisation. Broader concerns regarding the NDIS Review report recommendations for people with psychosocial disability have been documented by the National Mental Health Carers and Consumers Forum.⁵

NMHCCF Official Statement on the National Disability Insurance Scheme (NDIS) Final Report

Recommendation 1. We recommend that People with Disability are prioritised for State and Territory Government public housing.

Recommendation 2. We recommend that Federal Rent Assistance is increased and that the Federal Government provides financial incentives for private landlords to rent to NDIS

³Latest SIL and SDA Statistics from the NDIS August 2022 https://ndis.property/latest-sda-and-sil-statistics-from-the-

ndis/#:~:text=At%20current%20NDIS%20participation%20levels,the%20NDIS's%20assumption%20of%2006%25.&text=That%20equates%20to%20an%20additional,the%20end%20of%20June%202022).

Accessed 20/02/2024.

⁴ Action 7.2 Early Intervention Pathway for new participants pg. 135 - Independent Review into the National Disability Insurance Scheme: Final Report https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf

⁵ https://nmhccf.org.au/images/position-statements/NMHCCF-Official-Statement-on-the-NDIS-Review-Final-Report-Final.pdf_Accessed 20/02/2024.

participants at an affordable rate of rent. We recommend that equitable access to NDIS funded housing solutions (SIL, SDA, ILO) is upheld for people with psychosocial disability.

2. Transport

NDIS participants can be forced to travel to access appropriate support due to a lack of services where they live. The cost of travel by public transport or vehicle and fuel costs may act as a barrier in receiving the support we so desperately need. If we cannot afford the transport to access a NDIS service, then we can miss out on that service altogether. NDIS provides some transport funding, but not every participant is eligible for this. Our experience is that being approved for funding for transport can be subjective and arbitrary.

As one member of the APDC writes:

"I live approximately 52km from a regional city in a small rural town which takes about 45 minutes by road one way. There are no NDIS supports where I live. There is one Vline bus to the city and back per day which makes it impossible for me to use. I don't use public transport because I don't feel safe due to living with complex trauma. I also need to feel I have the means to escape any situation by car if the need arises. I do not like workers coming to my home as it is the only place I feel relatively safe. Then there is the issue of whether a worker would travel that distance.

I was denied transport funding on repeated occasions by NDIA Planners, despite having to travel to access supports. I was repeatedly told I am ineligible for the mobility allowance due to owning my own vehicle and my ability to drive a vehicle not being impacted by my disability. I was told I should move to a regional city to be able to access supports, completely ignoring the socioeconomic barriers I face as someone on a DSP, as well as the impact my psychosocial disability has on being able to move and live in an urban environment due to having Complex Post Traumatic Stress Disorder. The current rental housing and cost of living crisis has complicated issues further."

Recommendation 3. NDIS transport funding policy should be reviewed, and priority given to people in regional and rural areas where there is a lack of public transport.

3. Income

People with Psychosocial Disability living in regional areas can face systemic and socioeconomic barriers which prevent them from fully utilising the opportunities provided by

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the NDIS. Because of our disabilities many of us are on the Disability Support Pension or other Centrelink payments and thus can find our circumstances act as a barrier in terms of being able to access NDIS supports. For an example, to use our social and community participation funding we need to use our own money if we want to do activities such as going to the movies or a concert. This can be prohibitive to our social inclusion. If the NDIS wants us to use our own money, it is imperative that Centrelink payments are sufficient for our needs. In 2009 Bruce Bonyhady wrote an article for Future Leaders which said the DSP should be above the poverty level, for the NDIS to work effectively.

Recommendation 4. The Disability Support Pension and other Centrelink Payments that NDIS participants are on, should be raised above the Henderson poverty level.

4. Smaller budgets and underspend of plans by rural and remote participants

NDIA Data shows that NDIS participants in rural and regional areas are not funded equitably compared to participants in urban areas.

We found there are regional and remote inequities in plan size and spending, comparing participants who live in regional and remote Victoria to participants who live in major cities.

Mean core support plan sizes are \$3,300 smaller in regional and remote Victoria (\$57,300) in comparison to major cities (\$60,600). Spending on core supports was \$4,700 lower in regional and remote Victoria (\$29,500) in comparison to core plan spending in major cities (\$34,200).

Recommendation 5. The NDIA address the issue of long running planning and under-spend inequities experienced by people with a psychosocial disability living in rural, regional, and remote communities by co-designing solutions with participants and other stakeholders.

⁶ The NDIS in Victoria: are there inequities in participants' plan size and spending? Melbourne Disability Institute, University of Melbourne. Accessed 20/02/2024 https://disability.unimelb.edu.au/ data/assets/pdf_file/0003/4082178/Report-NDIS-in-Victoria-Ouantitative_FINAL.pdf

5. Supports

There are still too many barriers for regional and rural NDIS participants to be able to access appropriate NDIS supports of their own choosing. There can be thin markets which leads to a lack of available supports, and a lack of choice. Prices can be higher due to the lack of competition. Participants may feel uncomfortable with using support workers or therapists from their own area if they live in a small town due to concerns, they may have regarding protecting their privacy in a small community.

The fallout from issues such as mental illness and family violence are magnified for people living in regional and rural areas and are particularly sensitive issues for participants in their dealings with providers. It can be difficult for participants to get funding to cover the travel costs associated with using providers in other areas, both in terms of the transport cost for the participant, and the transport costs for the provider.

There may also not be the same opportunities for professional development for people working in regional and rural areas, which could have impacts on the quality-of-service provision.

Recommendation 6. Address thin markets by offering financial incentives to providers to work in areas with thin markets.

Recommendation 7. Ensure regional and rural participants get funded adequately for transport if they are using providers from outside of their own area.

Recommendation 8. Make sure professional development opportunities are available for workers in regional and rural areas.

6. Universal Registration

The APDC is very concerned by the recommendation in the NDIS Review that there should be universal registration of providers. Enforced registration to provide NDIS Services will increase the cost and to a further thinning of already thin markets in country Australia. As NDIS participants with a psychosocial disability, we want to be able to choose our own workers, they need to be first and foremost people we trust and can feel safe with and if we are limited to registered providers, that will reduce our choice.

Some workers who already provide supports under the NDIS to us will not want to register and will drop out of the NDIS support market altogether.

Already participants of the NDIS have been told by large, registered providers such as Wellways that they won't support them unless they require and are funded for at least 20 hours of support per week – and then ceased support to clients.

We are also concerned that the change to universal registration will benefit large providers at the cost of sole traders and small businesses, including peer support workers and Psychosocial Recovery Coaches. Larger providers do not focus on building relationships which are so important for psychosocial participants. Retaining access to unregistered providers is critical in rural areas because there is a smaller pool of workers and people running micro-enterprise will abandon the market if the cost of registration and auditing processes are too costly and onerous. Regional and rural participants already have less opportunity to negotiate costs of support and universal registration has the potential to push up costs.

Recommendation 9. Do not limit participant choice and control by introducing universal registration as per the NDIS Review recommendations.

7. Mental Health Services

There are more disabled people in rural and regional areas, and people in these areas also have worse health. For psychosocial participants the quantity, diversity and quality of mental health services differ greatly between rural and metropolitan areas.

An APDC member says:

"I have firsthand experience of the many barriers facing rural service users and how these are misunderstood and commonly dismissed by both the medical and mental health services. As a middle-aged woman, I also experience the challenges of rural women who often can't access support because of factors such as financial constraint, lack of public transport, lack of professionals to provide the sought support and distance required to travel to appointments."

Rural women can also be suddenly left without support because of personal factors such as relationship breakdown leaving them financially vulnerable, often homeless, and geographically isolated and external challenges such as service closures, funding cuts and lack of continuity of care because of the inability of rural areas to attract and retain health professionals.⁷

⁷ Rural and Remote Health Online Health Report Accessed 20/02/2024 https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health

Recommendation 10.

The introduction of foundational supports needs to consider the multiple challenges that consumer/survivors face in being heard, responded to and assisted by rural and regional health mental services. These challenges include the often-poor quality of services and supports provided by mental health services and the complete lack of choice and options that consumer/survivors experience when seeking support and care. The APDC recommend that individuals whether in the NDIS or in the yet to be established foundational supports system need to be able to choose and access support that they find meets their needs through the provision of individualised self-directed support funding. Enabling choice and control to be able to access supports outside of regional and rural centre-based state funded mental health services and into the broader market/sector is a right that people with a psychosocial disability wish to maintain/uphold.

8. Choice and Control

The is a high level of need to retain and optimise choice and control for people living in rural, regional, and remote communities. In regional and rural locations, the option of Virtual Online supports is paramount as access to suitably qualified and trained supports who NDIS participants with a psychosocial disability feel safe and capable of engaging will be highly limited and sometimes non-existent. As mentioned previously the need for participants with a psychosocial disability to be able to always feel that their privacy is protected is a deeply important. Engaging online with workers and allied health professionals who live in other regions or parts of the State is a preferred option for many participants. Changes proposed by the NDIS Review which will introduce mandatory NDIS worker registration and limit participant choices around preferred support are a backward step and have the potential to further lessen choice and control for NDIS Participants.

Recommendation 11.

The APDC strongly recommends that the Australian Government continues to support the full choice and support of all NDIS participant and rejects the NDIS review recommendation to introduce legislation and or policy that limits or restricts the rights of NDIS to retain full choice and control of whom they choose to provide them with their NDIS Supports

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