

Inquiry into NDIS participant experience in rural, regional and remote Australia

The Centre for Excellence in Child and Family Welfare (the Centre) is the peak body for child and family services in Victoria and Tasmania. For over 100 years we have advocated for the rights of children and young people to be heard, to be safe, to access education and to remain connected to family, community, and culture. We represent over 180 community service organisations, students and individuals throughout Victoria and Tasmania working across the continuum of child and family services, from prevention and early intervention to the provision of out-of-home care. Our members are spread across metropolitan, regional and rural areas.

The Centre welcomes the opportunity to provide a submission to the *Inquiry into experience of NDIS in rural Australia*. Our members work with families experiencing vulnerability and disadvantage, including children and families with disability and/or additional needs. Our members see firsthand the challenges families experience in trying to navigate the NDIS system and to access services and supports for their children.

Our submission focuses mainly on the following Terms of Reference:

- 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 NDIA in serving rural, regional and remote participants and
- c. Participants' choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those service.

Experiences of applicants and participants at all stages of the NDIS

All Australians with disability have a right to accessible mainstream services and supports. However, as the recent NDIS *Working together to deliver the NDIS* report shows, despite over ten years of the NDIS, change has been slow and many services remain inaccessible.¹ As we know from our members, this is exacerbated for participants located in regional, rural and remote locations. Currently, there are limited services available in regional and rural areas which can support participants from start to finish.

The journey through the NDIS, from application to plan implementation and review, has many obstacles. Our members have noted a markedly different experience for parents of young children with disability compared with parents of adult children when supporting their access and use of the NDIS. NDIA staff appear to assume that parents should be able to independently manage and coordinate their child's NDIS plan until they reach adulthood, at which point external supports might become more readily available. This expectation that parents of younger children should somehow manage makes accessing support more difficult than it should be as it implies judgement of parents. Additionally, when parents of younger children do obtain access to the NDIS, the importance of Support Coordination is often overlooked, despite its potential to significantly improve outcomes and reduce the need for supports in the longer term.

Member organisations in regional and rural areas have highlighted the following as issues:

- Professionals assisting families often do not know where to start, who to contact initially or what role they will be expected to play in getting a child or young person on to the NDIS.

¹ Commonwealth of Australia, Department of the Prime Minister and Cabinet. *Working together to deliver the NDIS*. NDIS Review: Final report. p.35.
<https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf>

- Application and extension forms are confusing, long and repetitive. One regional Child and Family Services Alliance in Victoria reported that some families have opted not to use the NDIS because they found it too hard to navigate.
- Language and terminology associated with accessing the Scheme can be confusing. Clients have struggled to understand the differences between plan managed, self-managed, plan co-ordinator and NDIA representative. They do not understand what their plan covers.
- Lengthy delays in plan reviews add to the challenges faced by participants living in rural areas.

These challenges faced by participants and their families, coupled with living in a rural area, compound barriers to access and the quality support they should receive from the NDIS.

Availability, responsiveness and effectiveness of NDIS support in regional areas

As the NDIS review highlights, there are still significant gaps in foundational support for disadvantaged communities in regional and rural communities. One of the major challenges for rural and regional participants is workforce, which is highlighted in the NDIS review. This includes lack of specialist services, lack of training/qualifications in support workers, and high staff turnover.

Currently, over 33 per cent of participants – who have been in the Scheme for at least one year – are not accessing any therapeutic supports in small and medium rural towns, despite having funding.² Because of the limited availability of services in regional and rural areas, participants either go without services, have no choice or control in relation to providers, accept non-preferred or inferior quality services due to lack of options, or buy in services from larger regional services which involves significant travel.

Planners should be able to take into account the needs of participants in more isolated areas and delegates should be able to approve additional core or other funding to enable travel – either by specialist providers or by regular providers who need to visit multiple times. The Centre recommends that NDIS planners be given practical guidance to take into account the needs of participants in remote areas. The Centre also notes the urgent need to address the attraction and retention of new and existing allied health professionals in rural and regional areas, through a contemporary NDIA workforce strategy.

The classifications of rural, regional and remote do not reflect the reality that many children, young people and families face when attempting to access supports through the NDIS. Families do not need to be in a 'remote' area to have this barrier to access. For example, someone who lives only 50-100 kilometres from Albury-Wodonga or a similar regional centre (and is therefore considered 'rural' under the NDIS) can find themselves with no access to local providers.

Much of NDIS plan funding is spent on travel and administration fees. For example, if a family services practitioner spends time emailing an NDIS provider, talking to them on the phone and attending meetings which can involve travel – this is costed out from the NDIS package funds.

² Department of Social Services. (2023). Analysis of NDIS market using NDIS monthly datasets as of 30 June 2023. Unpublished.

The Centre welcomes Action 13.2 in the NDIS review, which calls for the NDIA to progressively roll out provider panel arrangements for allied health supports in small and medium rural towns.³ However, panel arrangements only focus on providers and professionals already operating in these rural towns.⁴

Participant choice and control over NDIS services

Most of the challenges affecting choice and control are systemic. The concept of choice and control is undermined if services are not available, take a long time to access, are costly, or if support workers are not completing mandatory/incident reports. System barriers such as long waitlists affect the extent to which choice and control can be exercised. For example, in the north-east of Victoria, clients have struggled to access NDIS supported services due to long waitlists and services not accepting new referrals. Some clients have accessed tele-health but not all clients are able to do so and many clients prefer a face-to-face engagement. Because of the extensive wait times, early intervention support is dragged out, NDIS funds are not used in a timely way and the value of the packages reduces. Choice and control is also affected by the complexity of documents and processes, for example, when Plan documents are not easy to read and when language and processes are not easily accessible or understood.

The 2015 NDIA Integrated Market, Sector and Workforce Strategy (the strategy) acknowledged that providing choice will be more difficult in rural and remote areas and would require greater market facilitation.⁵ The strategy made clear that the thin market segments of rural and remote locations would require cross-sectoral coordination, facilitated through the NDIA's Rural and Remote Servicing Strategy.⁶ At the time of writing, neither strategy has been updated to reflect the current stage of the Scheme and the challenges faced by service providers and participants post-pandemic. The NDIS Review also makes no mention of either of these strategies. The Centre recommends these strategies be updated to reflect current workforce and participant challenges.

Any other related matters

As has been well documented through various disability reviews and submissions, the NDIS is a document-heavy process which requires good levels of literacy and cognitive function to successfully navigate. The process needs to be much more accessible and easier for participants and professionals regardless of whether they are in regional, rural or metropolitan areas.

NDIS workers and providers are not legally obligated to provide a Working With Children Check or Criminal Record check. Any individual can start an ABN and advertise themselves as a provider and begin working with families. Our members have raised this as a concern given the vulnerability of children with disability.

³ Ibid. p.11.

⁴ Ibid. p.184.

⁵ National Disability Insurance Scheme. (2015). Integrated Market, Sector and Workforce Strategy. p.10. https://www.dss.gov.au/sites/default/files/documents/07_2015/ndis_integrated_market_sector_and_workforce_strategy_june_2015.pdf

⁶ National Disability Insurance Agency. (2016). Rural and Remote Strategy. p.36. <https://www.ndis.gov.au/about-us/strategies/rural-and-remote-strategy>

In conclusion

The Centre has previously prepared submissions into the NDIS and would be pleased to provide additional insights as needed. We welcomed the NDIS review, particularly recommendations 13 and 14, which will directly impact the service quality and experiences of rural and regional participants.

However, despite the NDIS website referring to the NDIS Review as 'being among the most comprehensive and accessible Commonwealth reviews in history', the report had little to say about children and young people with disability who live in care. This is a significant gap in the review and affects children and young people across the state not only in regional and rural areas.

The Centre looks forward to an opportunity in the future where we might discuss with the Joint Standing Committee on the National Disability Insurance Scheme the invisibility of children and young people with disability in care and how their needs can be much better supported.