Joint Standing Committee on the National Disability Insurance Scheme

NDIS Participant Experience in Rural, Regional and Remote Australia

Rare Voices Australia Submission

February 2024

About Rare Voices Australia

Rare Voices Australia (RVA) is the national peak body for the estimated two million Australians living with a rare disease. RVA provides a strong, unified voice to advocate for policy as well as disability, health and other systems that work for people living with a rare disease. RVA's work is non-disease specific and is based on the commonalities of the approximately 7,000 different rare diseases. RVA advocates for the best outcomes for Australians living with a rare disease, including those impacted by disability.

Rare diseases are often serious and progressive, exhibiting a high degree of symptom complexity, leading to significant disability, health, and psycho-social challenges. While not all people with a rare disease have an associated disability, those who do experience substantial and permanent disability impacts.

RVA welcomes the opportunity to provide a Submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) on matters related to NDIS participant experience in rural, regional and remote Australia.

National Strategic Action Plan for Rare Diseases

RVA's Submission is closely aligned with the Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan)[1], the first nationally coordinated effort to address rare diseases in Australia.

The foundational principles of the Action Plan are also at the heart of the challenges facing the NDIS and are areas of focus for this Submission:

- Person-centred
- Equity of access
- Sustainable systems and workforce.

The Action Plan identifies people living with rare disease in regional, rural and remote areas and people experiencing socio-economic disadvantage as a priority population.

> *"Australians living in rural and remote areas experience poorer health and welfare outcomes, including higher rates of chronic disease, disease burden and mortality (death) compared to those living in metropolitan areas. This inequity is likely exacerbated when people living in regional, rural and remote areas are also living with a rare disease as they have lower access to health services, and are more likely to present to hospital with conditions that could have been treated by a primary health care practitioner.*
>
> *For Australians living with a rare disease, including an undiagnosed rare disease, living in regional, rural and remote areas may have implications in terms of:*
>
> - *receiving a timely and accurate diagnosis;*

> - *continuity of care and access to appropriate treatments; and*
> - *having higher exposure to modifiable risk factors…"*
>
> *– National Strategic Action Plan for Rare Diseases*[1]

Specific disability-related actions and implementation steps from the Action Plan highlight the need for coordinated and integrated care and are presented in Appendix 1.

RVA's Submission references The McKell Institute's 2019 report, *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases* (*Disability & Rare Disease Report)*[2] which informed the Action Plan.

The *Disability & Rare Disease Report* identified that over 77 percent of people with rare disease in regional Australia have unmet needs for healthcare services, including 15 percent who did not have their healthcare needs met at all. When asked about assistance with care needs, the problem was worse in rural Australia where over 80 percent reported not having their needs fully met, including over one in four people reporting that their needs for assistance were not met at all.

Those surveyed living in regional and rural areas indicated a satisfaction rate of between 40-46 percent with the NDIS.

> *"The separation of funders which has occurred under the NDIS between the disability and health sectors has created gaps in service provision, which in contested spaces, can impact individuals with rare disease that have an underlying medical cause of their disability. This is evidenced by the high number of people reporting in the Rare Disease survey that the NDIS worsened their situation."*
>
> *– Disability & Rare Disease Report*[2]

National Disability Insurance Scheme Independent Review

In October 2022, the Australian Government commissioned the NDIS Independent Review to examine the design, operations, and sustainability of the NDIS and to consider ways to make the market and workforce more responsive, supportive and sustainable.

The *Working together to deliver the NDIS: Independent Review into the National Disability Insurance Scheme Final Report* (*NDIS Review Report)*[3] was released on 7 December 2023.

In June 2023, RVA was pleased to provide a detailed submission to the NDIS Review[4] for consideration, which included recommendations for improvements across five (5) themes:

> **1. Engagement and Collaboration:** Building ongoing sustainable engagement and collaboration arrangements between the National Disability Insurance Agency (NDIA) and RVA.

2. **Knowledge and Capability:** Embedding rare disease knowledge and capability within the NDIA through defined roles.

3. **Policy, Procedures and Practice:** Improving NDIS policies, procedures, and practices.

4. **Data Management:** Improving NDIS rare disease data management to better inform decision-making and policy development.

5. **Other Sector Interfaces:** Improving the interface between the NDIS and health, housing, early childhood and education, and recognising the specific needs of people with disability and participants with rare diseases.

RVA acknowledges and thanks the NDIS Review Panel for its consideration and recommendations for the considerable transformation of the NDIS.

RVA continues to advocate for policy and practice that supports the sustainability of the NDIS while upholding participants' rights to 'choice and control' and provides for both equitable access to services and supports, and equitable outcomes for all Australians living with a disability.

In this Submission, we draw attention to these five (5) themes and highlight recommendations from the NDIS Review that warrant consideration within the scope of this inquiry.

RVA's Submission to the Terms of Reference

In preparing this Submission, RVA engaged with our RVA Partners (rare disease groups/organisations) and individuals and families living with rare disease in regional, rural and remote areas of Australia. We have included quotes and excerpts from their responses in this Submission and thank them for their contribution.

The challenges and impacts of people with rare disease and disability in regional, rural and remote areas of Australia are considerable and require significant policy improvements, market innovation, and adjustments to NDIS capability and practice to ensure equitable access and outcomes.

With reference to the Terms of Reference of this inquiry, we offer the following:

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

"In regional and rural Australia, rare diseases are even more rare. Some professionals aren't familiar with the rare disease your child has. NDIS funding varies based on what they write. It is important to source the right professionals for your family and in rural and regional areas this is limited."

The current process for determining NDIS eligibility and access based on diagnosis poses challenges. For people living with rare disease in general, and for the cohort living in regional, rural remote areas, these challenges are exacerbated.

People living with rare disease can have challenges with diagnosis due to a lack of access to specialists in their geographical location, and many report a 'diagnostic odyssey' that can take years and require frequent visits to specialists that may be hours away or interstate. In some cases, a diagnosis explaining all symptoms may be unattainable (known as undiagnosed rare diseases).

Medical specialists and allied health practitioners may not have much experience interacting with the NDIS and may be unfamiliar with the language used, eligibility criteria and the required evidence to support NDIS Access applications. They may struggle to adequately articulate their current and future disability support needs.

"I have found that NDIS support is tied directly to the professionals around us and their understanding of our situation, their understanding of the NDIS, the diagnosis or symptoms and what that means, and their willingness to advocate accordingly and appropriately to the NDIS for the needs your family is requiring."

NDIS Access rejection can be high in this population and may translate into repeated NDIS Access applications that are time-consuming, costly, and traumatic for the participant.

For people who do gain access to the NDIS, the ongoing inability to gather the necessary evidence/reports can also negatively impact the planning development and review process and subsequent allocation of recurring funding.

Access to non-NDIS alternative supports and services in the local community can be extremely limited with extensive waitlists. Additionally, alternative supports and services may be difficult to access due to geographical proximity, or non-existent due to thin markets. Therefore, the needs of people living with rare disease and disability may go partially or completely unmet, making impacts significant.

RVA supports the intent of **Recommendation 1** of the NDIS Review: **Invest in foundational supports to bring fairness, balance and sustainability to the ecosystem supporting people with disability,** including the actions to develop and implement a Foundational Supports Strategy, Community Care Programs, and navigation support for people with disability who are not recipients of the NDIS. Design and implementation of these initiatives must ensure equitable access for Australians living in regional, rural, and remote Australia.

"Getting to understand the NDIS requires a lot of time which is something you don't have and can't facilitate easily in the bush especially during times of immense stress and pressure e.g. drought or flood."

RVA also supports **Recommendation 3** of the NDIS Review: **Provide a fairer and more consistent participant pathway** and notes that any change to eligibility and access based on functional capacity (and not diagnosis) will require equitable access to assessors across Australia, including through telehealth. We support improvements to application processes and accompanying guidance to make the application process more transparent, simple, and equitable.

There are significant disparities in NDIS plan spending between participants in regional/remote areas and those in major cities. For example, the NDIS Review reported that over a third of participants in small and medium rural towns are not accessing any of the therapy supports they are funded for.

This is due to a combination of socioeconomic factors, lack of access to community connectors and navigators, and limited access to workforce and services. This underutilisation of NDIS funds can incorrectly convey reduced support needs and lead to plan reductions following plan reassessments.

RVA supports **Recommendation 4** of the NDIS Review: **Support all people with disability to navigate mainstream, foundational and NDIS service systems.**

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

"On my son's entry to the NDIS I was told by all of the professionals (therapists and LACs) that it was an amazing budget for our situation. I was told that the NDIS wouldn't fund more than one piece of equipment per year. There was no one else I could talk to. I heavily relied on these people and there are very few of these types of professionals to choose from in rural areas. For all I knew, this was the gospel. I eventually found that in fact my son was able to access a lot more through services, equipment and support through the NDIS. It really didn't sit well with the LAC or therapists when I began to question them. It didn't really sit well with me that I didn't have a lot of choice."

RVA Partners (rare disease groups/organisations) reported that NDIA/ Local Area Coordinators (LAC) advice is inconsistent and can result in wide variability from participant to participant with the same or similar rare disease. There is also limited opportunity to request a change in Planner or LAC or to escalate issues if people feel their individual circumstances were not adequately understood.

NDIA staff and their partners in the community working in regional, rural or remote locations may not encounter many people living with a particular rare disease or be aware of the range of barriers people with disability face in these geographical locations.

RVA has heard from community members that this can result in wide variability in NDIS plan funding and approved supports for the same condition between participants in capital cities and those in regional environments. There is also wide variability between participants in regional environments across different states.

People living in regional, rural and remote communities may not have a local support group or know of others living with the same rare disease, and so they have limited channels available to them to assist with navigating the complexity of the NDIS.

In some cases, there is the added complication of limited access to the internet, however, participants are directed to the NDIS website as the primary channel for information and resources. Such participants are therefore heavily reliant on the guidance provided by NDIA staff regarding what is reasonable, necessary and available support.

To improve the consistency, equity and participant experience, RVA recommends that the NDIA engage with RVA as the national peak body for Australians living with a rare disease to build rare disease knowledge and capability across its LACs, Navigators, and NDIA assessors/planners through rare disease training and access to evidence-based information.

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

"We know of several families that have moved from rural to metropolitan regions in order to access services for their child. A family in remote Queensland reneged on an employment contract and returned to Brisbane after their son was diagnosed with a rare disease. The mother stated that the town had no allied health services, a visiting GP and pharmacist, and the travel to metropolitan areas for appointments was unmanageable."

People living with rare disease and disability in regional, rural and remote areas report that there is a critical need for a skilled workforce capable of addressing rare diseases and complex needs in these regions. Persistent workforce shortages limit access to suitable supports, placing pressure on existing workers. The scarcity of service providers creates thin markets, leading to long waitlists. Retaining access to quality supports is limited due to staff turnover.

Travel costs make in-home supports and mobile allied health services unsustainable within current plan funds, and in many cases, services do not extend outside the metropolitan areas as it is not economical or financially attractive for providers.

These factors can combine to compromise participant functioning, safety, and well-being. In some cases, participants and their families choose to relocate to metropolitan areas.

There is intense competition for staff across the health, aged care, education, and disability sectors in these geographical areas. Workforce incentive programs exist for the other sectors with the exception of the disability sector.

Governments need to develop targeted employment and training models for the disability, care and support sectors that focus on building a capable, attractive, and retainable workforce for rural, regional and remote areas. This includes creating incentives for service providers to operate in these locations and ensuring continuity of support.

The development of innovative workforce strategies such as portable training and leave balances could encourage retention and skill development within the sector.

Funding agreements or contracts with specialist providers could help build professional capacity among non-specialist providers in remote areas, enhancing the overall quality of care.

"In the bush it's not just rare diseases that are rare, it's disability in general! There's no support group out here to ask for help. You can't find out who a decent support worker is, whether there is a particularly good support coordinator that is worth approaching or who has trialled the latest equipment. The only way to try is to buy.

It would be extremely helpful to be able to source assistance from the NDIS to find these people and supports, and to make allowances for suitable workers to travel without soaking up too much of the participant's budget."

RVA believes a whole-of-community approach should be explored to develop models for better integration of NDIS funding and services with other health and human services to ensure a holistic approach to care and support.

RVA notes **Recommendation 14** of the NDIS Review**: Improve access to supports for First Nations participants across Australia and for all participants in remote communities through alternative commissioning arrangements.**

As RVA understands, for the proposed 'alternative commissioning arrangements' to work, it will require the NDIA, First Nations communities, remote communities, other Australian Government agencies and state and territory governments to work together as partners to buy or 'commission' supports for people in the community to improve access.

Additionally, 'integrated commissioning' will pool and streamline these commissioned supports across disability, health, and aged care to provide access to services, minimise costly service duplication, and remedy the glaring gaps in support.

RVA believes these ideas are worthy of exploration, however, we caution against a 'one size fits all' approach to the commissioning model. We recognise the complexity of this endeavour and seek to participate in the co-design of services to protect against the loss of choice and control and to ensure access to specialist expertise and the necessary skills to meet the disability support needs of many people living with rare disease in regional, rural and remote areas.

"Support workers in our regional area are mostly engaged in aged care and they don't seem to have the capacity to take on extra work outside their existing jobs. So we have people in our community in residential care who receive a lot of support and then others with complex syndromes and disabilities who receive none. Parents are left to do all of the personal care role. And community access? It just doesn't happen when you're working to keep the farm going."

RVA recognises the merits of **Recommendation 13** of the NDIS Review**: Strengthen market monitoring and responses to challenges in coordinating the NDIS market including actions to:**

- Roll out provider panel arrangements for allied health supports in small and medium rural towns, or in areas with persistent supply gaps, to enhance service delivery and access. Provider panels will utilise good providers already in operation and aim to reduce service delivery costs through coordinated travel and shared resources.
- Develop tools to help participants connect with each other, navigators, and providers for specific supports in targeted locations.
- Through the Disability Reform Ministerial Council, all Australian governments should agree and publish a provider of last resort policy, ensuring continued access to supports where markets fail, or no non-government provider is willing or able to offer supports.
- Ensure a broader strategy to maintain access to critical supports for participants, even in scenarios where service delivery is compromised, such as natural disasters, or when addressing the needs of clients with very complex needs, including in regional, remote and rural settings.

“There are a lack of support workers and sometimes finding one in a small community can be a real challenge. I was given approximately 70 hours of support work within my son’s first budget. My child has significant round-the-clock support needs. We live on a rural property about 25km from the nearest small town and over an hour away from the nearest regional centre.

How do you find a support worker in a small rural town and only offer them 70 hours of work for the year? Calling around the various support worker suppliers results in never-returned calls or, ‘So where are you calling from? I don’t know if anyone will travel that far’…”

RVA has heard from individuals and organisations that the cost and logistics of travel for therapists and support services to remote, regional and rural locations are significant barriers to service delivery. Relying on individual NDIS plans to cover travel costs is inefficient and inequitable. Instead, the Government must restructure travel cost policies and improve telehealth access to ensure all participants can access services regardless of location. This could include funding travel for therapists, contracting providers for remote outreach, and integrating NDIS funding with other health services.

Where physical service provision is limited, the NDIS should expand access to telehealth and other remote support options as a temporary measure to bridge service gaps, ensuring access to appropriate technological infrastructure to enable service access.

Although NDIS packages include some funds for the cost of therapists and NDIA staff travel, they do not include funding for NDIS package holders and their carers to travel for appointments, meetings with medical practitioners to gather necessary information for planning purposes or accommodation costs when traveling distances that require overnight stays.

"For rural Australians it would be much easier if there were a bucket of funding we could apply for in certain situations to have our own support worker travel with us to specialist appointments, hospital visits, and therapies that would not necessarily be taken from our budget. To find accommodation for the support worker on top of our needs is prohibitively expensive but to have a random stranger provide support in the city is just not workable. We are left with no choice but to struggle on our own."

d. the particular experience of Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse (CALD) backgrounds, and participants from low socio-economic backgrounds, with the NDIS

The emphasis on cultural sensitivity and engaging local communities, especially in designing and delivering services, is crucial for the success of the NDIS in remote and First Nations communities and for participants from CALD backgrounds.

RVA is concerned by the lack of culturally appropriate and affordable services for Aboriginal and Torres Strait Islander participants, particularly in rural and remote areas. The NDIA must engage with communities directly to understand their specific needs and preferences for culturally appropriate services.

Recommendation 14 highlights the need for community-led and place-based alternative, integrated and community commissioning approaches to improve outcomes significantly for First Nations communities and all participants in remote areas.

RVA supports the recommended approach to alternative integrated and community commissioning services for remote and First Nation communities, emphasising place-based and community-driven support delivery built on community strengths. Such approaches would allow communities to create their own culturally safe services, addressing the current lack of appropriate supports.

There should also be a commissioning strategy for navigation supports, ensuring that navigators are embedded within communities, have strong local knowledge, and can provide tailored support.

RVA heard from regional, remote and rural community members who identified financial stress as a limiting factor in being able to afford travel and transportation over long distances to access disability services.

"People who don't live rurally have no idea how hard it is or how far you have to travel to get services – let alone rare disease-specific disability services."

e. any other related matters.

Specialist Disability Accommodation (SDA): There's a need for commissioning SDA in areas where the private investor model fails to meet the needs, especially for those living in remote locations or with complex needs. People with rare disease can have severe and progressive functional impacts and require access to SDA in their local community regardless of geography.

The NDIS Review recommends a shared support model for people in supported independent living, however, provisions are required to be made for people in regional, rural and remote communities where shared living and/or shared support models are not possible or viable.

Partnership between the NDIA, state, and territory governments, and communities is crucial.

Carer Support: Carers in regional, rural, and remote areas reported feeling overwhelmed by the competing nature of running a family household, navigating the complexities of the NDIS, managing the impacts of rare disease, and long-distance travel.

Consideration must be given to sustaining regional, rural and remote carers to enable people with rare disease and disability impacts to continue residing with their family and in their local community. This represents both a quality-of-life consideration and a long-term value-for-money option.

Access to Adaptive Equipment: Parents of children living in regional, rural and remote locations reported that they do not have the same access to community facilities that children with a disability in capital cities have in relatively close proximity (e.g. accessible playgrounds, community activity, and play spaces, etc.).

However, NDIS applications for adaptive/accessible play equipment (i.e. adaptive swings) for use on rural properties where no alternatives exist within the greater region have been unsuccessful. In developing a Foundational Support Strategy, and early childhood intervention, consideration should be given to a shared pool of disability-specific adaptive play and mobility equipment that participants can hire to create equitable experiences for all children.

> ***"If we are not counting rare diseases, people living with rare diseases do not count."***
>
> *– National Strategic Action Plan for Rare Diseases*[1]

Data management: In Australia, there is a significant gap in our health and disability information systems regarding the data on most rare diseases. Currently, there is no unified strategy to collect, analyse and utilise existing data. There's an evident need for a national, coordinated, and systematic strategy to gather and apply rare disease data, including the use of registries. This strategy would allow for continuous monitoring and the accumulation of knowledge about rare diseases, consequently informing clinical practice, research, and health and disability service planning.

At present, it's unclear how many individuals with a rare disease are NDIS participants, how many have applied unsuccessfully for NDIS access, or how many have chosen not to apply due to concerns about losing access to their essential health supports. We do not know how many NDIS participants living with rare disease are in regional, rural or remote locations.

RVA believes the NDIS should adopt a coordinated and collaborative data collection framework for the coding of rare diseases, including undiagnosed rare diseases, that is consistent across disability and health and identifies people living in regional, rural and remote locations.

We acknowledge the challenges faced by the NDIS in tracking and measuring rare diseases are not unique. Both Commonwealth and state approaches remain disjointed, and no single approach can serve as a universal template. Nevertheless, we welcome the opportunity to work with the NDIA to improve data coding for rare diseases within the NDIS. Detailed data reports can then inform strategic policy, decision-making processes, research efforts, and workforce initiatives across the disability sector. It can assist in driving innovation and translate research into evidence-based disability support and care.

RVA is encouraged by the government's commitment to the National Disability Data Asset (NDDA). This platform will provide a single source of information combining Commonwealth, state, and territory data on people with disabilities, significantly enhancing research, policy development and service delivery. RVA eagerly anticipates participating in the design and implementation of the NDDA to ensure the needs of people with disabilities who also have a rare disease are recognised as an important cohort.

RVA supports **Recommendation 23** of the NDIS Review: **Measure what matters, build an evidence base of what works, and create a learning system.**

Summary

RVA and the rare disease sector acknowledge the transformative role the NDIS has played in funding and supporting disability in Australia. RVA supports all efforts that seek to provide an integrated care model for people living with rare disease and disability impacts and equitable access to services, supports and quality outcomes.

We believe the specific challenges faced by people with disability living in regional, rural and remote locations require a substantial policy response and welcome the opportunity to co-design future policy with the NDIS and state and federal governments to deliver improved experiences and outcomes for the thousands of NDIS participants with rare disease living in metropolitan, regional, rural and remote locations across Australia.

Thank you for the opportunity to contribute to this inquiry.

Appendix 1

Disability and the National Strategic Action Plan for Rare Diseases

Specific disability-related actions and implementation steps from the Action Plan include:

Action 2.1.1: Provide rare disease care and support that is integrated, incorporating clear pathways throughout health, disability and other systems.

Implementation

2.1.1.2. To reduce fragmented care, ensure policy meets people's full range of needs, including health, disability and education. Support this work with a cross-jurisdictional, cross-sectoral working party.

Action 2.1.2: Build a broad range of care and support services that are responsive to the changing needs of people living with a rare disease and their families.

Implementation

2.1.2.1. Develop an accessible multi-purpose digital repository, incorporating elements targeted at the workforce that supports people living with a rare disease. With access to adequate information, health care and social support professionals will be equipped to support people living with rare disease and their families to navigate health, disability, and other systems.

2.1.2.3. Through regular stakeholder consultations, determine strategies to improve access to rare disease care and support services for Aboriginal and Torres Strait Islander people, those with CALD backgrounds, those living in rural and remote areas, and other priority populations.

References

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3. Commonwealth of Australia, Department of the Prime Minister and Cabinet. *Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report.* Oct 2023. Available from: https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis [Accessed February 2024]

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