NDIS Quality and Safeguards Commission

Consultation on Proposed Changes to NDIS Act (Bill No.2) - Quality and Safeguarding Amendments

Rare Voices Australia Submission

December 2024

About Rare Voices Australia

Rare Voices Australia (RVA) is the national peak body for the estimated two million Australians living with rare disease disability impacts. This includes the estimated 100,000 NDIS participants with severe to profound rare disease disability impacts.

RVA provides a strong, unified voice to advocate for policy and systems that support equitable and effective access to disability, healthcare, 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. Our person-centred focus sees us working with all key stakeholders, including people living with a rare disease, over 100 RVA Partners (rare disease groups/organisations), governments, key peak bodies, researchers, clinicians, and industry.

RVA led the development of 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. RVA is now leading the Action Plan's collaborative implementation on behalf of the rare disease sector.

Australians with rare diseases face unique and systemic challenges, including complex support needs, limited specialist knowledge, and fragmented services. This submission highlights the potential impact of the proposed legislative reforms on the rare disease community and advocates for their specific needs within the NDIS.

What Is a Rare Disease?

A disease is rare if it affects fewer than five in every 10,000 people. There are approximately 7,000 different diseases and an estimated two million Australians live with a rare disease. Therefore, while the occurrence of individual rare diseases is uncommon, having a rare disease is in itself relatively common.

Around 80% of rare diseases have a genetic origin and due to the hereditary nature of some rare diseases, multiple people within the same family can be impacted.

Rare diseases are often serious and progressive, exhibiting a high degree of symptom complexity, leading to significant disability, health, and psycho-social challenges.

Most people with a rare disease meet the Australian government's definition of having a disability, being a "limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities". Based on NDIS data, RVA estimates 100,000 NDIS participants are living with rare disease disabilities.

For key decision-makers at all levels, greater knowledge of rare diseases can facilitate more responsive and appropriate services for people living with a rare disease and their families and carers.

RVA's Submission

RVA welcomes the opportunity to contribute to the National Disability Insurance Scheme (NDIS) Quality and Safeguards Commission consultation regarding the proposed legislative reforms to the NDIS Act 2013 to strengthen the safeguarding powers of the NDIS Commission.

RVA recognises that following this consultation, the NDIS Commission intends to release an exposure draft of the proposed NDIS Amendment (Getting the NDIS Back on Track No. 2) Bill[2], which is expected to be introduced to the Australian Parliament in mid-2025.

RVA is committed to ongoing engagement with the NDIS Commission to ensure that the exposure draft and any subsequent legislative changes reflect the needs of the rare disease disability community. Many individuals with rare disease disability impacts are among the most complex and vulnerable NDIS participants, often requiring intensive and specialised support.

RVA seeks to ensure the proposed amendments prioritise high-quality care and effective safeguards, fostering a more inclusive and equitable system for people with rare disease disabilities, while also ensuring sustainable service provision, particularly in regions where there are underserved markets.

The following is RVA's detailed response and recommendations to the NDIS Commission's consultation areas.

Penalty Framework and Statutory Requirements

- **Statutory Duty of Care and Due Diligence**

The introduction of statutory duties for NDIS providers and their key personnel represents an important step in ensuring participants receive high-quality, safe supports. The rare disease community often requires coordinated, multidisciplinary support teams, making accountability essential to prevent gaps in service delivery.

The final report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability[3] (Disability Royal Commission) raised concerns about NDIS providers failing to take responsibility for the safety and wellbeing of participants. The Disability Royal Commission found many cases of providers poorly monitoring participant health and well-being, sometimes resulting in a health condition worsening without intervention and access to proper medical treatment.

Many NDIS participants living with rare diseases have complex health co-morbidities that must be effectively managed alongside their disability impacts. RVA believes significantly increasing health literacy among support services is critical to improving the overall quality and safeguarding of NDIS participants with rare disease disabilities. However, there is also a pressing need to ensure provider sustainability in underserved areas, where rare disease participants often experience the greatest challenges. Balancing accountability measures with market sustainability is vital to maintaining access.

Recommendations:

1. The NDIS Commission develops clear guidelines to accompany these statutory duties to ensure providers understand their obligations in complex care contexts.

2. The NDIS Commission incorporates mandatory training programs focused on rare disease awareness and care practices to ensure compliance in these unique cases.

3. The NDIS Commission provides support for providers operating in thin markets to meet their statutory duties to limit administrative burdens and ensure their sustainability.

- **Penalties and Offences Framework**

RVA supports the proposal to align penalties for breaches of the NDIS Act with those in comparable regulatory frameworks such as workplace health and safety. Stronger deterrents will help to address the systemic failures identified by the Disability Royal Commission, particularly in cases where non-compliance leads to participant harm.

Recommendations:

4. Ensure compliance frameworks are proportionate to the size and capacity of the provider. This is important to avoid discouraging smaller, specialised providers who may be vital to rare disease participants, particularly priority populations, and people living in regional, rural, and remote settings, from entering the market.

5. Create pathways for providers to rectify issues before penalties are enforced, particularly in cases where non-compliance stems from resource constraints rather than negligence.

- **Anti-Promotion Orders**

RVA believes the proposal to empower the NDIS Commissioner to issue anti-promotion orders to irradicate misleading advertising and exploitative marketing practices is a necessary reform to protect all NDIS participants from financial and emotional harm.

- **Evidentiary Certificates**

The proposal to allow evidentiary certificates signed by the NDIS Commissioner to be prima facie evidence is a welcome measure to streamline legal processes. However, RVA recognises the need to balance efficiency with participants' rights to contest such evidence.

Recommendation:

6. Implement clear mechanisms for participants and providers to challenge the accuracy of evidentiary certificates to maintain fairness and transparency.

Safeguarding

- **Expansion of Banning Orders**

RVA supports the proposal to expand the categories of individuals against whom banning orders may be imposed, including auditors and consultants. Many people living with rare disease disability impacts are reliant on highly specialised services and providers. Ensuring the integrity and safety of all individuals involved in the delivery of these supports is critical to preventing harm to participants. Expanding the list of individuals who may face banning orders to include subcontractors and intermediaries (including plan managers and support coordinators) involved in coordinating or influencing service delivery will further safeguard participants from systemic risks.

Recommendation:

7. Expand the list of individuals who may face banning orders to include subcontractors and intermediaries (including plan managers and support coordinators) involved in coordinating or influencing service delivery.

Information Gathering

- **Shortened Timeframes for the Production of Information or Documents**

Timely access to accurate information is critical for safeguarding participants, particularly those with rare disease disability impacts, complex support needs, and high levels of vulnerability, who may require urgent interventions.

RVA supports the NDIS Commission's proposal to clarify the NDIS Act 2013 to enable them to request both documents and information and that, in certain circumstances, the NDIS Commissioner may request the production of these in less than the current 14-day timeframe.

- **Data Storage Requirements**

RVA is aware that many NDIS providers hold and retain highly sensitive data and information about NDIS participants, including personal details and health and medical information. We are concerned that there is currently no requirement for NDIS providers to hold information within Australia and that this data may not be appropriately secure, safeguarded, or accessible.

RVA supports the proposed changes that will require NDIS providers to hold information relating to NDIS participants and the delivery of NDIS supports in Australia on Australian-based servers, as is the standard requirement for many government-funded services.

Conclusion

RVA commends the Australian Government for proposing these legislative changes to strengthen the quality and safeguarding framework of the NDIS and the powers of the NDIS Commission.

We welcome the opportunity to provide detailed stakeholder briefings to the NDIS Commission on behalf of the rare disease community and to collaborating with the NDIS Commission to uphold the rights and well-being of NDIS participants living with rare disease disabilities.

Contact:
Fiona Lawton
Disability Advocacy Manager
Rare Voices Australia
Email: info@rarevoices.org.au

References

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2. Commonwealth of Australia, Department of Social Services. *Major increases to penalties and criminal offences planned for NDIS providers*. (Media Release. 28 October 2024). Available from: https://ministers.dss.gov.au/media-releases/16496 [Accessed December 2024].

3. Commonwealth of Australia, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability Final Report (2023) volumes 1-12. Available from: https://disability.royalcommission.gov.au/publications/final-report [Accessed December 2024]