Submission to the Senate Community Affairs Legislation Committee

Inquiry into the National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026

July 2026

Rare Voices Australia

Second Submission

Contents

Rare Voices Australia's Submission

Introduction

Rare Voices Australia (RVA) appreciates the Committee's consideration of our May 2026 submission and welcomes the opportunity to provide this supplementary submission. RVA urges the Committee to undertake further examination of how the National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026 (the Bill) will identify, assess and **safeguard National Disability Insurance Scheme (NDIS) participants with rare disease disability and complex and high-intensity support needs.**

This cohort includes people living with rare disease disability who often experience **multiple interacting impairments, progressive or fluctuating functional impacts, disability-related health support needs** and for whom there may be limited condition-specific evidence. Some live in households where more than one family member has the same genetic condition or related rare disease disability, creating complex and overlapping participant, carer and family support needs.

RVA remains concerned that these participants are likely to be among the **most vulnerable** if the Bill continues to permit the Minister for the NDIS to apply support determinations across all participants and relies on standardised assessments or automated decision-making. This is because rare disease disability is often atypical, multi-system and poorly represented in datasets, standard assessment tools and what may be considered strong peer reviewed evidence.

For this cohort, the proposed standardised process is **likely to underestimate need** by assessing impairments in isolation, overlooking supported functioning, missing disease progression, or failing to recognise the **cumulative impact of multiple impairments**. Automated or data-driven tools may compound these risks where there are **too few comparable cases to produce reliable recommendations**.

Despite representing an estimated **100,000 participants within the NDIS**, people living with **rare disease disability remain largely invisible** within NDIS reporting, monitoring and evaluation systems. Without meaningful identification, the government, the National Disability Insurance Agency (NDIA) and the community will be unable to determine whether the reforms are improving outcomes for this cohort or inadvertently **increasing inequity, risk and unmet need**. For this reason, RVA continues to advocate for the NDIA to adopt a **rare disease disability identifier**.

RVA recommends further targeted legislative amendments to strengthen NDIS sustainability while preserving safety, equity, procedural fairness and individualised support for participants with rare disease disability and other highly complex conditions.

RVA calls on the Committee to safeguard people living with rare disease disability and their families and carers by recommending the following critical amendments to the Bill:

Recommendations

1. Require consideration of cumulative disability impacts by recognising the combined functional effect of **multiple impairments**, **secondary conditions and comorbidities** when determining eligibility, support needs and funding.

2. Introduce a **High-Risk Participant Framework** for people with rare disease disability and other high-complexity conditions, that includes additional safeguards, expedited reassessment pathways and protection from blanket support reductions.

3. Legislate **an individual safety assessment** before support reductions, reassessments, support determinations or participant exits take effect, and prohibit decisions that would create a significant risk of harm.

4. Establish a **transparent framework for AI and automated decision-support,** including explainability, independent auditing, bias testing for underrepresented cohorts, human rights oversight and participant notification when AI contributes to a decision.

5. Require **meaningful human decision-making** for all participant decisions, including access, reassessments, support determinations, funding levels, plan variations, plan renewals and Scheme exits.

6. Preserve procedural fairness by **maintaining access to internal review and independent merits review** through the Administrative Review Tribunal for decisions affecting eligibility, supports and funding.

7. **Protect rare disease evidence pathways** by requiring decision-makers to consider the best available evidence for rare and ultra-rare conditions, including specialist clinical expertise, lived and caregiver experience, patient-reported outcomes, registry and natural history data, and international clinical guidance.

8. Require **assessment of the family and informal support capacity** before relying on informal supports, including where multiple family members live with rare disease disability, carers hold multiple caregiving roles, and the intensity of the support exceeds ordinary parental responsibility.

Detailed Background to the Recommendations

Recognise Cumulative and Multiple Impairments

A central concern with the Bill is the assumption that disability can be accurately understood through discrete impairments and standardised assessment methodologies.

Rare disease disability commonly affects multiple impairment domains simultaneously, including intellectual, cognitive, neurological, sensory, physical and psychosocial functioning. The disability impacts and support needs often arise from the interaction of these impairments, rather than from a single qualifying impairment assessed in isolation.

Therefore, the legislation should explicitly require decision-makers to consider the cumulative functional impact of multiple impairments, comorbidities and secondary conditions when determining eligibility, support needs and funding levels.

Recommendation

1. Amend Schedule 1, Part 3 to clarify that NDIS supports may be funded where the need arises from the cumulative, combined or interacting effects of a participant's permanent impairments and disability-related conditions, including impairments that were not individually relied upon to meet NDIS access requirements but contribute to the participant's functional limitations and support needs.

Establish a High-Risk Participant Framework

The Bill continues to treat participants largely as a single cohort despite clear differences in complexity, vulnerability and risk. RVA remains concerned that there is no mechanism to identify participants with rare disease disability, whose health, safety and wellbeing could be significantly affected by relatively small changes to supports.

People with rare disease disability are disproportionately represented among participants requiring disability-related health supports, intensive behavioural supports, specialist communication supports, complex care arrangements and 24/7 supports. They are also more likely to live with progressive or neurodegenerative conditions and episodic and fluctuating impacts that require responsive and flexible planning. For these participants, relatively small reductions in support can create immediate risks to safety, health and family sustainability.

RVA remains concerned about any proposals that assume shared support arrangements for people who require 24/7 supports. Many people living with rare disease disability require one-to-one support, continuous clinical monitoring, highly personalised support arrangements, and carers or support workers with specialist training and expertise. Applying such assumptions without adequate consideration of

individual circumstances risks compromising participant safety, wellbeing, quality of care and support outcomes.

RVA maintains that rare disease disability should be recognised within the legislation as a cohort that may require enhanced NDIS decision-making safeguards. The Bill should require the NDIA to identify participants whose disability characteristics, support needs or health risks create heightened vulnerability to adverse outcomes resulting from support reductions, reassessments, automated decision-making or participant exits.

Recommendation

- Insert a legislative mechanism requiring the NDIA to identify participants with rare disease disability, high-complexity conditions and elevated risk of harm, and apply enhanced safeguards including senior decision-maker oversight, expedited reassessment pathways, additional evidence gathering and protection from blanket support reductions.

Require Individual Safety and Harm Assessments

The Committee has recognised concerns regarding support determinations and participant safety. For people with rare disease disability, support reductions can contribute to functional decline, avoidable hospitalisation, behavioural escalation, increased use of restrictive practices, provider withdrawal, carer burnout and family breakdown. These risks may not be apparent through standardised assessments or administrative processes.

Therefore, RVA supports the introduction of a legislative requirement that the NDIA undertake an individual safety and harm-risk assessment before implementing support determinations, funding reductions, reassessments, plan renewals or participant exits where there is potential for adverse impacts on health, safety or wellbeing.

Recommendation

3. Legislate a safeguard requiring an individual safety assessment before support reductions, reassessments, support determinations or participant exits take effect and prohibit decisions that create a significant risk of harm.

Establish Safeguards for AI and Automated Decision-Making

The Committee has acknowledged concerns regarding automation. RVA supports the appropriate use of technology to improve efficiency, consistency and administrative performance. However, artificial intelligence (AI) should support professional judgement, rather than replace it.

Rare disease disability presents a unique challenge for machine-assisted decision-making systems because:

- datasets are small
- variation between individuals is high
- disease trajectories are unpredictable
- support needs are highly individualised.

AI systems perform most reliably where data is large, patterns are stable and circumstances are relatively predictable. Historical datasets often underrepresent rare disease participants. AI systems trained on population-level data are therefore at increased risk of producing inaccurate recommendations for rare disease disability cohorts.

RVA believes the legislation should establish a clear AI decision-making framework for the NDIS. Transparency, explainability, independent auditing, bias testing and human rights oversight should be mandatory features of any future AI-supported decision-making process. Participants should be informed whenever AI tools have contributed to a decision.

RVA recommends that, before automated decision-making powers are expanded within the NDIS, the Bill be amended to require implementation of the safeguards and oversight mechanisms identified by the Royal Commission into the Robodebt Scheme[1]. This includes mandatory human oversight, transparency, accountability, review rights and independent auditing.

Recommendation

4. Require the NDIA to establish a transparent legislative framework governing the use of AI and automated decision-support systems that incorporates the recommended safeguards from the Royal Commission into the Robodebt Scheme.

Require Meaningful Human Decision-Making for all Participant Decisions

RVA believes no decision affecting a participant's eligibility, supports, reassessment outcome, funding level, plan variation or transition from the NDIS should take effect without meaningful human review. Human oversight must involve genuine consideration of the participant's circumstances, available evidence and specialist clinical advice.

Recommendation

5. Legislate a requirement for all participant-related decision-making to have a human decision-maker ultimately responsible. Human oversight must involve genuine consideration of the participant's circumstances and evidence, rather than simply endorsing an automated recommendation.

Preserve Participant Review Rights

People living with rare disease disability are particularly vulnerable to the impacts of standardised assessment and decision-making processes. If an assessor lacks expertise in a rare condition, an inaccurate assessment may result in significant reductions to a participant's supports. Review rights are therefore especially important for people with uncommon and medically complex conditions, who must have meaningful opportunities to challenge decisions that do not accurately reflect their circumstances.

Without effective review rights, participants may have no practical way to correct decisions that underestimate their disability, overstate family capacity, or create serious risks to their health, safety and wellbeing.

Recommendation

5. Maintain full access to internal review and independent merits review through the Administrative Review Tribunal for decisions affecting eligibility, reassessments, support determinations, participant funding, plan variations and plan renewals.

Protect Rare Disease Evidence Pathways

RVA continues to raise concerns regarding the evidence requirements in the proposed Bill. Collectively, rare diseases affect an estimated two million Australians, however, individual rare diseases affect small populations. As a result, many conditions lack large-scale clinical trials, extensive peer-reviewed research or broad population datasets. The absence of evidence is often a consequence of rarity rather than an indication that a support lacks value or necessity.

Participants should not be disadvantaged because their condition is too rare to generate large-scale evidence or because the scientific literature relating to their condition is inherently limited.

Specialist clinician evidence, international clinical guidance, natural history studies, disease registry data, caregiver evidence and lived experience evidence often provide the most reliable understanding of support needs. These forms of evidence should be explicitly recognised within the legislative framework.

RVA believes the NDIA can improve rare disease disability visibility through recognised international classification systems such as Orphanet. Improved identification of rare disease participants would support better planning, policy development, service design and evaluation of reform impacts.

Recommendation

7. Amend the Bill to require decision-makers to consider the best available evidence relevant to rare and ultra-rare conditions, including:
    - specialist clinical expertise
    - lived and caregiver experience
    - patient-reported outcomes
    - registry and natural history data
    - recognised rare disease classification systems.

Recognise Rare Disease Family and Carer Capacity

RVA remains concerned that the proposed framework places excessive reliance on assumptions about the availability, capacity and sustainability of informal supports within families.

The Bill and associated rules increasingly frame supports as matters that families should provide unless they can be demonstrated to exceed "ordinary parental responsibility". For many rare disease families, however, the care provided extends far beyond the expectations of ordinary parenting. It is frequently highly skilled, intensive, clinical, continuous and complex, often substituting for supports that would otherwise be delivered by disability, health and community services.

RVA believes the legislation must explicitly distinguish between:

- ordinary parental responsibilities for a child of the same age without disability; and
- disability-related supports arising from a child's impairment, health complexity, behavioural support needs, communication needs, supervision requirements, medical vulnerability or progressive condition.

Without this distinction, there is a significant risk that extraordinary levels of disability-related care will be inappropriately characterised as parental responsibility, resulting in increased pressure on families and reduced access to necessary supports.

These concerns are particularly relevant for rare disease families, where disability and caring responsibilities often affect multiple individuals within the same household or family network. Parents, partners, siblings, adult children and extended family members may simultaneously manage their own disability or health conditions while providing care and support to one or more relatives with rare disease disability. Many also balance

employment, financial pressures, care coordination, advocacy responsibilities and interactions across multiple service systems.

RVA believes that the NDIS should not make blanket assumptions about the availability of informal care, nor presume that family members can absorb additional caring responsibilities in place of funded supports. Decisions regarding informal supports should consider whether such support is available, appropriate, safe, sustainable and reasonable in the individual circumstances of the participant and their family.

In particular, the legislation should require consideration of circumstances where:

- multiple people within a household or family live with disability
- family members have their own disability, health or age-related support needs;
- carers undertake multiple or dual caregiving roles
- caring responsibilities exceed those ordinarily expected for a family caring for a child of the same age without disability
- the withdrawal or reduction of funded supports would place carers at risk of burnout, financial hardship, workforce disengagement or adverse health outcomes.

The availability of family members should not be used as a substitute for reasonable and necessary disability supports **where the level, intensity, frequency, duration or complexity of care exceeds what would ordinarily be expected of informal supports.** This safeguard is particularly important for rare disease families, who often provide lifelong, highly specialised and medically complex care that is critical to the health, safety and wellbeing of the person with disability.

Recommendation

8. Amend the Bill to explicitly distinguish ordinary parental responsibilities from disability-related support needs where the level, intensity, duration or complexity of care exceeds what would ordinarily be expected of informal supports and require decision-makers to assess parental responsibility against the needs of a child of the same age without disability.

Conclusion

RVA supports measures that strengthen the integrity and long-term sustainability of the NDIS. However, sustainability must be achieved without reducing safety, equity or appropriate support for participants with rare disease disability and other high-complexity conditions.

The recommendations outlined in this submission provide practical safeguards that would strengthen the Bill while protecting participants who are most at risk of unintended consequences from standardised assessment processes, support determinations and automated decision-making.

RVA would welcome the opportunity to appear at a public hearing to assist the Committee to better understand how rare disease disability presents in the NDIS, why the proposed safeguards may be insufficient for this cohort, and what practical amendments are needed

Contact

Fiona Lawton

Disability Advocacy Manager

Rare Voices Australia

Email: fiona.lawton@rarevoices.org.au

About Rare Voices Australia

Rare Voices Australia (RVA) is the national peak body for Australians living with a rare disease. RVA's work is non-disease-specific and is based on the commonalities of approximately 7,000 different rare diseases. Our person-centred focus sees us working with all key stakeholders in the rare disease sector, including people living with a rare disease, governments, key peak bodies, researchers, clinicians, and industry.

RVA collaborates with over 100 rare disease groups/organisations (RVA Partners) in Australia that are consumer-led groups/organisations, to provide a strong, unified voice. RVA advocates for the best outcomes for Australians living with a rare disease, and their families and carers.

RVA recently joined the NDIS Disability and Carer Organisations Forum and is a member of the NDIS Neurodegenerative, Palliative Care and Rare Disease Advisory Group.

RVA is proudly delivering the Rare Disease Disability Project (the Project) for the National Disability Insurance Scheme (NDIS) through the Peer Support and Capacity Building grant. As part of the Project, RVA leads the Rare Disease Disability Network (RDDN) which is a peer support and capacity building network for rare disease community-led groups/organisations and invited sector stakeholders.

Contributions from RDDN members and people living with rare disease disability have informed this submission.

What Is a Rare Disease?

A disease is a condition with a specific pattern of clinical signs, symptoms, and findings, and is considered rare if it affects fewer than, or equal to, 5 in 10,000 people [1]. There are approximately 7,000 different rare 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 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[1]. Rare diseases are often serious and progressive, exhibiting a high degree of symptom complexity, leading to significant disability, health, and psycho-social challenges.

Rare Disease Disability

Most people with a rare disease meet the Australian Government's definition of having a disability, which is defined as a "limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities."[2,3]

This includes the estimated 100,000 NDIS participants with severe and profound rare disease disability impacts.

Rare disease disability is characterised by:

- complex, multi-system and progressive conditions
- permanent impairments linked to genetic or congenital origins
- frequently involve multiple impairments and comorbid conditions
- may have intensive behaviours and high safeguarding risk
- highly individualised lifelong disability-related and intensive support needs.

The disability impacts of rare diseases remain poorly recognised in policy and funding settings, despite being experienced by nearly all people living with a rare disease. This lack of recognition contributes to inconsistent support, fragmented care and avoidable inequities.

To address the challenge of responding to more than 7,000 different rare diseases, RVA has created the following 5 broad rare disease disability categories:

1. **Neurological/neurodevelopmental** – conditions that affect the brain, nerves, or how the brain develops.
2. **Progressive/degenerative** – conditions that get worse and more serious over time.
3. **Episodic/fluctuating** – the impacts come and go and can change from day to day.
4. **Children with delayed development** – children who take longer to learn and do things.
5. **Undiagnosed rare disease conditions** – there is currently no name or explanation for the condition.

Many NDIS participants with rare disease disability rely on the Scheme for NDIS supports that enable participation in daily life, maintain functioning, engage in employment and study, sustain their living and family arrangements, and maintain independence.

Their needs do not fit neatly into standardised frameworks, are under-represented in NDIS data and population modelling, and include some of the most complex and highly funded participants in the NDIS.

National Strategic Action Plan for Rare Diseases

RVA led the collaborative development of the Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan)[4], the first nationally coordinated effort to address the needs of rare diseases in Australia. RVA is now leading the Action Plan's collaborative implementation on behalf of the rare disease sector.

Aspects of the Action Plan specifically address the NDIS and the arbitrary and unhelpful line that is often drawn between health and disability. In particular, the Action Plan highlights the need for coordinated and integrated care (**see Appendix 1**).

The Action Plan is built on three foundational principles:

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

These principles directly support the recommendations in this submission.

References

1. Commonwealth of Australia. Royal Commission into the Robodebt Scheme: Final Report. Canberra: Commonwealth of Australia; 2023. Available from: https://robodebt.royalcommission.gov.au/publications/report [Accessed July 2026].
2. Australian Government. Australian Public Service Commission. Definition of disability. September 2019. Available from: https://www.apsc.gov.au/working-aps/diversity-and-inclusion/disability/definition-disability [Accessed July 2026]
3. Australian Bureau of Statistics. Disability, ageing and carers, Australia: Summary of findings. July 2024. Available from: https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#disability [Accessed July 2026]
4. Commonwealth of Australia. Department of Health. National Strategic Action Plan for Rare Diseases. Canberra; 2020. Available from: https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf [Accessed July 2026]

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.