Submission to the Senate Community Affairs Legislation Committee

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

May 2026

Rare Voices Australia Submission

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What Is a Rare Disease?

A disease is considered rare if it affects 5 in 10,000 people or fewer.[1] There are around 7,000 rare diseases, and an estimated two million Australians live with a rare disease. While individual conditions are rare, rare disease collectively is common.

Around 80% of rare diseases have a genetic origin, and some affect multiple family members.[1] Rare diseases are often serious, progressive and complex, creating significant disability, health and psychosocial challenges.

About Rare Disease Disability

Most people with a rare disease meet the Australian Government's definition of disability.[2,3] This includes an estimated 100,000 National Disability Insurance Scheme (NDIS) participants with severe and profound rare disease disability impacts. This cohort includes people with neurodevelopmental syndromes, mitochondrial disorders, progressive neurological conditions, metabolic disorders, and undiagnosed rare diseases.

Rare disease disability is characterised by:

- Complex, multi-system and progressive conditions characterised by multiple impairments and significant co-morbidities.
- Significant permanent impairments linked to genetic or congenital origins.
- High likelihood of challenging behaviours with high safeguarding risk.
- Highly individualised lifelong disability-related and intensive support needs.

Rare disease disability remains poorly recognised in policy and funding settings, contributing to inconsistent support, fragmented care and avoidable inequity.

Many NDIS participants with rare disease disability rely on the NDIS to maintain daily functioning, independence, participation, employment, study and family stability.

These participants are under-represented in NDIS data and include some of the most complex and highly funded people in the NDIS. They are particularly vulnerable to reforms that do not explicitly consider their unique needs.

The recommendations in this submission are intended to build in safeguards that ensure the safety and wellbeing of rare disease disability participants and their families and carers.

Executive Summary

Rare Voices Australia (RVA) supports measures that strengthen the integrity and long-term sustainability of the NDIS. However, the *NDIS Amendment (Securing the NDIS for Future Generations) Bill 2026* (the Bill) represents a fundamental shift away from the NDIS' rights-based, individualised design toward a more standardised and capped service model. This model can only work if adjacent systems are strengthened to absorb displaced needs and costs.

RVA does not support the passing of this Bill as drafted. The proposed reforms will disproportionately disadvantage people with rare disease disability whose needs are often more complex, multi-system, progressive and highly individualised.

RVA is particularly concerned the Bill will result in:

- Reduced parliamentary oversight of key funding and policy decisions.
- Weaker procedural fairness and review safeguards for participants.
- Eligibility criteria based on standardised functional assessments that do not reflect complexity or real-world functioning.
- Exclusion of comorbid and non-qualifying impairments from funding consideration.
- Reliance on foundational supports that are not yet fully established.
- Reduced flexibility in planning, reassessment and responsiveness to change.
- Evidentiary requirements that are not fit-for-purpose in a rare disease disability context embedding existing systemic inequity.

These reforms risk underestimating need, compromising participant safety and wellbeing and shifting cost to already overwhelmed families.

RVA is deeply concerned about the absence of mechanisms to identify and protect **high-risk participants, including those requiring 24/7 care, disability-related health supports or high-intensity behaviour support.**

Reform must not come at the cost of safety, equity or access for people with rare disease disability. These reforms create a foreseeable risk of deterioration, crisis, hospitalisation and harm to participants and caregivers. Sustainable reform requires a differentiated, risk-informed approach that recognises complexity and protects those with the highest needs.

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) **Protect people's rights and individualised planning**
   a) Retain strong protections for choice, control and individualised planning.
   b) Preserve procedural fairness, internal review and independent merits review.
   c) Maintain accessible and responsive reassessment and plan variation pathways.

2) **Ministerial powers**
   a) Apply statutory limits, oversight, transparency and review to Ministerial funding decisions.
   b) Prohibit blanket funding cuts, levelling measures and category-based reductions where such reductions would compromise a participant's safety, health, functional capacity, stability or participation.
   c) Require that any reductions are proportionate, evidence-based and demonstrably safe at an individual level.
   d) Ensure that any reduction in funding below assessed need is subject to transparent justification and merits review protections.

3) **Identify and protect high-risk cohorts**
   a) Create a legal mechanism to identify rare disease disability and other high-risk cohorts.
   b) Exempt high-risk cohorts from blanket cuts and use tailored assessment, planning and monitoring.
   c) Do not reduce supports, including staffing ratios, needed for safety, essential functioning, or prevention of deterioration or restrictive practices. Prohibit category-based reductions for participants who require:
      i) 24/7 or continuous support.
      ii) Disability-related health supports.
      iii) High-intensity behaviour support.

4) **Apply a risk-proportionate framework**
   a) Require a risk assessment before any funding reduction, covering safety, deterioration, behavioural escalation, restrictive practices and carer capacity.
   b) Do not proceed where a high risk of harm is identified.
   c) Do not reduce funding below reasonable and necessary support needs.

5) **Whole-of-person, multiple-impairments approach**
   a) Use holistic assessments that capture complexity, fluctuation and real-world functioning.
   b) Recognise the interaction and cumulative impact of multiple impairments and comorbidities, including for Australians living with undiagnosed rare disease.

c) Recognise the intersectionality of rare disease disability and other priority populations, including Aboriginal and Torres Strait Islander people, people living in regional, rural and remote areas, and people from culturally and linguistically diverse (CALD) backgrounds.

6) Broaden acceptable evidence

a) Recognise lived experience as valid evidence in assessment and planning.
b) Recognise specialist clinical input as valid evidence for rare disease disability.
c) Allow other evidence where peer-reviewed or generalisable evidence is limited for small cohorts.

7) Remove inappropriate treatment tests

a) Recognise the permanence of rare, genetic and congenital conditions.
b) Do not make eligibility or support contingent on:
   i) Treatment pathways that do not alter the underlying impairment.
   ii) Unrealistic, ineffective or clinically inappropriate treatments.
   iii) Treatments that are inaccessible because of cost or location.
   iv) Treatments that are only available through clinical trials.

8) Carers and families

a) Do not increase reliance on informal care.
b) Strengthen income support, respite and disability-appropriate childcare so families do not absorb support gaps.

9) Transition safeguards

a) Do not remove participants from the NDIS, or materially reduce supports, until appropriate foundational and mainstream disability supports are operating.
b) Require safeguarding checks and human oversight for decisions affecting safety, continuity or legal rights.

10) Address financial and equity gaps arising from the proposed model.

Recommend reforms to the:

a) **Carer Payment -** reflecting the actual economic value of unpaid care.
b) **Disability Support Pension -** enabling co-contribution to essential supports.
c) **Child Care Subsidy to expand and** adequately support children with disability needs.
d) **Education system to fund increases** that significantly improve Inclusion Support Programs.
e) **Chronic Disease Management Plan** changes to increase access to additional allied health sessions.

11) Co-design reform

a) Embed lived experience and rare disease disability expertise in policy design, implementation and evaluation.

Detailed Background to the Recommendations

Key Systemic Risks for Participants with Rare Disease Disability

The Bill creates several overlapping risks for participants with rare disease disability:

- **Under-recognition of complexity -** functional and impairment-based frameworks do not capture the multi-system and cumulative nature of rare disease disability.
- **Structural underfunding -** budget caps, funding reductions and tighter eligibility can create a mismatch between need and funded support.
- **Transition gap risk -** participants may exit the NDIS before equivalent foundational and adjacent supports are in place.
- **Increased inequity -** people with rare disease disability may be more likely to be excluded or underfunded.

Ministerial Powers

The Bill would confer Ministerial powers to allow system-level funding reductions across support categories with limited parliamentary oversight or constraints and, limited assurance that individual circumstances will be considered.

For people with rare disease disability, this creates risk that decisions affecting essential supports, including disability-related health supports, high-intensity assistance, and supports for community access, employment and education, will occur without sufficient transparency, scrutiny, or consideration of individual circumstances. These supports are fundamental to safety, stability and daily functioning.

Reducing these supports does not remove need; it transfers cost and risk to other parts of the system, including into crisis, acute, and informal care systems.

Reducing funding without individual reassessment is a significant departure from individualised planning and risks undermining that core feature of the NDIS.

If system-level funding mechanisms are to be introduced, they must be accompanied by safeguards that ensure **no participant is placed at risk of harm, regression, or loss of essential functioning.**

RVA advocates for statutory safeguards including:

- Explicit limits on the scope of Ministerial decision-making.
- Requirements for transparency, justification and public reporting.
- Parliamentary oversight mechanisms.

Partial Funding and Inequities

The expansion of system-level funding controls creates a **foreseeable shift toward a partial funding model**, particularly for participants with complex, multi-system needs such as those with rare disease disability.

Under the Bill:

- Funding may be capped at a system level.
- Support categories and ratios may be reduced or standardised across participants.
- Supports must be linked narrowly to qualifying impairments rather than total functional impact.

In practice, these mechanisms mean the NDIS may no longer fully fund assessed reasonable and necessary supports. For participants with rare disease disability, whose needs arise from the interaction of multiple impairments, this creates a high risk that **overall need will be underestimated and partially funded**.

Where funding falls below the cost of delivering supports, providers may withdraw or cease services, particularly in thin, regional or highly specialised rare disease disability markets.

Where supports remain available but underfunded, **the gap is transferred directly to individuals and families**, who may be forced to:

- Fund essential therapies required to maintain function providing they can afford to.
- Reduce or forego necessary support worker hours.
- Delay or avoid assistive technology.
- Cut back on transport and participation supports that enable employment, education and social inclusion.

This would create systemic inequity where access to essential supports is increasingly determined by personal financial capacity, geographic location, and the ability to navigate complex systems. This outcome is fundamentally inconsistent with the NDIS as a **universal, rights-based scheme**, designed to provide equitable access based on need rather than means.

Reducing Categories of Support

The Bill enables the Minister to reduce funding for entire categories of supports through legislative instruments, including participation supports. These reductions are not limited to a single policy decision but may be varied, expanded or re-applied over time, without individualised assessment and merits review.

This creates ongoing uncertainty and risk that supports may be reduced below levels required not only for participation, but also for basic safety, health, stability and daily functioning, regardless of assessed need.

Regarding the current proposal to reduce participation supports by up to 50%, for participants with rare disease disability, participation supports that enable employment, education and community life are essential and often require skilled, consistent support. Reducing these supports increases the risk of isolation, functional decline, crisis and long-term reliance on more intensive systems.

For high-intensity participants, reducing these supports may also increase the use of restrictive practices, loss of autonomy, and further limit rights.

RVA calls for legislative safeguards that limit the use and impact of support determinations across all categories of supports, ensuring that funding **cannot be reduced below the level required to meet a participant's assessed reasonable and necessary needs across all categories of support.**

High Risk Cohort

People with rare disease disability already face systemic disadvantages, and the proposed reforms risk worsening this inequity. The Bill contains no mechanism to identify and respond to different participant cohorts.

RVA recommends formally **recognising rare disease disability as a high-risk cohort** because it is associated with:

- **Complex, permanent and often multi-system conditions** with high-intensity support needs.
- Being rarely attributable to a single impairment **with support needs that arise from the interaction of multiple conditions.**
- **Neurodegenerative, life-limiting progression**, with episodic and fluctuating presentation.
- **Intensive behaviours** and high safeguarding risk.
- Reliance on **disability-related health supports.**
- Support requirements that are dynamic**, high-intensity and lifelong.**
- Higher staffing ratios to **maintain safety and stability.**

These participants are under-represented in data and modelling despite having some of the most complex and resource-intensive needs in the NDIS. RVA continues to call for the introduction of a rare disease disability universal identifier within the NDIS dataset to ensure this cohort is visible, and to enable more accurate, evidence-informed and equitable policy, funding and support decisions.

Risk Proportionate Approach

RVA is particularly concerned about proposals for broad funding adjustments, including levelling supports across categories such as social and community participation by up to 50 per cent.

For participants who need continuous or 24-hour support, funding directly affects safety, continuity of care and essential functioning. For this cohort, cuts to funding, support intensity or staffing ratios may pose higher risk and have immediate and serious consequences.

RVA recommends a **risk-proportionate approach to funding and implementation**, and the inclusion of explicit safeguards for participants who require:

- Disability-related health supports.
- High-intensity behaviour support.
- Higher staffing ratios to maintain safety and stability.

- Continuous and intensive care, including nursing and ventilation.
- 24/7 support.

Reducing supports below what is needed for safety and stability increases the likelihood of deterioration, crisis and avoidable reliance on acute and emergency systems. Reducing behaviour support and other high-intensity services increases the likelihood of escalation, harm, family and provider stress, and reliance on restrictive practices.

If social and community connection and participation supports are arbitrarily reduced for this high-risk cohort, such reductions may result in:

- Regression in daily living skills.
- Increased risk of injury.
- Neglect and social isolation
- Reduced capacity to engage in employment and community life.

These outcomes may destabilise families, providers and the workforce, especially in thin and specialised markets.

The Bill must expressly recognise high-risk participants and implement statutory safeguards that prohibit blanket or category-based funding reductions. Additionally, it should preserve support ratios where they are linked to safety and behaviour support.

Narrowing of Impairment-related Funding

Limiting NDIS funding to needs arising "directly" from impairments that meet the disability eligibility criteria is a fundamental shift that does not reflect how disability is experienced.

Rare disease disability is rarely attributable to a single qualifying impairment. Instead, it typically arises from the combined and interacting effects of multiple impairments, secondary conditions, and comorbidities, which together determine a person's functional capacity and support needs.

Restricting funding to discrete impairments risks fragmenting disability into artificial components, failing to account for the cumulative and compounding impact of complex conditions. This approach would systematically underestimate need and is inconsistent with the NDIS' established focus on functioning and lived experience.

Disability support must recognise that functional limitations arise from the totality of a person's impairments and their interaction, not from individually assessed impairments in isolation.

RVA calls for the Bill to be revised to remove the requirement that supports must arise "directly" from a qualifying impairment and instead **explicitly recognise cumulative functional impact**, so that people with rare and complex conditions are not disadvantaged by artificial distinctions that do not reflect lived experience.

Functional Capacity Assessments and Access Criteria

The move to **standardised functional capacity assessments** for NDIS access raises serious concerns for rare disease disability, which is often complex, progressive and fluctuating.

Standardised functional assessments often fail to capture:

- The cumulative impact of multiple impairments.
- The episodic, fluctuating and progressive nature of rare diseases.
- Real-world functioning and dependency on supports.

Assessing capacity in controlled or theoretical settings creates a structural bias toward under-assessment for participants whose functioning depends heavily on supports and context.

A more diagnosis-agnostic approach may improve consistency for some participants, but for many people with rare disease, diagnosis provides essential context about progression, variability and cumulative impact. Removing that context risks underestimating need and underfunding supports.

Functional assessments must be **fit-for-purpose for rare diseases**, and incorporate clinical judgement, and lived experience.

Evidence Requirements

The Bill's increased reliance on **generalisable, peer-reviewed evidence** creates systemic barriers for rare disease disability cohorts, where:

- Research is often limited due to small populations.
- Peer-reviewed, generalisable evidence is often limited or still emerging.
- Treatments and interventions are highly individualised.
- Lived experience is a critical source of insight into effective support.

When systems privilege generalised evidence over lived experience and specialist clinical expertise, people with rare disease disability are pushed further to the margins and may lose access to necessary supports.

RVA has repeatedly raised the inequities of this approach in **submissions to the NDIS Evidence Advisory Committee.**

For rare and ultra-rare diseases, lived experience and caregiver-reported outcomes must be recognised as **primary evidence sources**, particularly where clinical literature is sparse or non-generalisable.

Decision-making should also give **weight to specialist clinical evidence**, particularly from clinicians with recognised expertise in the specific rare disease, over generalised functional or standardised assessment tools.

Treatment Exhaustion and Permanence

Tighter permanence criteria and treatment exhaustion requirements do not reflect the reality of rare disease disability.

Requiring treatment exhaustion:

- Ignores permanence of genetic conditions.
- Delays access.
- Increases deterioration risk.

Many rare diseases have treatments that may ease symptoms but do not remove the underlying impairment. The condition remains permanent, and functional impacts often remain significant even when symptoms fluctuate.

Requiring treatment exhaustion in this context delays support, creates inequitable barriers, and increases the risk of deterioration while participants gather evidence of an already permanent impairment.

Reduced Flexibility and Responsiveness

Restrictions on reassessment, plan variation and day-to-day flexibility pose risks for people with rare disease disability, whose conditions are often progressive, fluctuating or unstable and whose support needs can change quickly.

For this cohort, flexibility is a core safeguard that allows the NDIS to respond to real-world complexity and prevent deterioration, crisis and potentially avoidable hospitalisation.

If reassessment and plan variation are narrow, slow or highly prescribed, the system becomes less able to respond to change, shifting risk and burden onto participants, families and providers.

The Bill's reliance on "unanticipated" changes to family or carer capacity is too narrow. In rare disease contexts, carer burnout and family breakdown are often foreseeable, so the NDIS **must respond to preventable as well as unexpected** collapse.

RVA is calling for a **rapid assessment pathway for participants with rare disease disability**, so that changes in function can be responded to early, before preventable decline becomes a crisis.

These risks are compounded by **greater reliance on automated or rules-based decision-making**. Rare disease participants are statistical outliers whose needs are often poorly represented in standard datasets and planning assumptions.

For people with rare disease disability, certainty must come from timely human review, responsive plan changes and genuinely individualised decisions. The Bill should preserve accessible reassessment and variation pathways, including a rapid pathway for significant change in function.

Increasing Reliance on Family and Carer Supports

The Bill suggests families and informal supports will be considered before NDIS funding is provided. In rare disease disability, that assumption is often unsafe because care may occur in families where multiple people are affected by rare disease disability or carers are also NDIS participants.

Rare disease families already provide substantial unpaid care while navigating fragmented systems under financial and emotional strain.

The impacts are:

- More unpaid labour.
- Reduced workforce participation.
- Heightened financial stress.
- Increased risk of caregiver burnout and harm.
- Reliance on restrictive practices for families supporting people with complex behaviours.

These reforms also risk deepening fragmentation by forcing families to **navigate sharper divisions between funded and non-funded impairments, NDIS and non-NDIS supports, and disconnected service systems**.

In rare disease disability contexts, this increases administrative burden, makes holistic care harder to coordinate, and is likely to widen inequity by favouring families with greater financial resources, health literacy and advocacy capacity.

These realities reinforce the need for genuine co-design with people with rare disease disability, families, carers and representative organisations. Any reform that increases reliance on informal care should be matched by **reform of the carer support system**.

Transition to Foundational Supports

The Bill and associated reforms rely on expanded foundational supports for people excluded from the NDIS or receiving lower levels of support needs.

These supports are **not yet fully developed, consistently available, or proven to meet the needs of people with complex disability. This creates a significant risk of service gaps during transition.**

People with rare disease disability rely on multiple systems working together including the NDIS, health, education, housing and community services. Tightening boundaries between those systems without improving coordination risks creating service gaps.

The sequencing of reform is critical. Tightening eligibility or reducing supports before alternatives are operational creates a **foreseeable risk of harm, service disruption and unmet need.**

RVA strongly recommends that no participant should lose NDIS supports until **equivalent, accessible and appropriate alternatives are demonstrably in place.**

Thriving Kids

Children with rare disease disability are at particular risk under these reforms. There is a real concern that children with complex, multi-system and often progressive conditions may be diverted into early supports or foundational programs, such as Thriving Kids, despite having needs that are more appropriately met through the NDIS.

While early childhood and foundational responses may be suitable for some children with developmental concerns, they are **not an equivalent substitute** for an individualised disability support scheme for children with complex and high intensity needs.

As raised in RVA's submission to the Inquiry into the Thriving Kids Initiative, inappropriate diversion risks **delayed access to essential supports, avoidable functional decline, increased family burden, and missed opportunities for early intervention** that could stabilise functioning and reduce long-term support needs.

Conclusion

RVA supports reform that strengthens the integrity and long-term sustainability of the NDIS. However, reform must still adequately support people whose needs cannot be standardised. Rare disease disability is a key test of whether the NDIS can remain flexible, safe and equitable. Targeted co-design with RVA and people with lived experience of rare disease disability is therefore essential.

This submission demonstrates that, without amendment, the Bill risks reducing support, shifting responsibility and costs across systems, and weakening fundamental safeguards for people with rare disease disability.

RVA calls on the Committee to safeguard people living with rare disease disability and their families and carers by recommending the critical amendments to the Bill included in this submission. RVA welcomes the opportunity to **present at the public hearing** and support the development of a framework that works safely and effectively for people with rare disease disability.

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About Rare Voices Australia

RVA is the national peak body for Australians living with a rare disease. RVA works across the approximately 7,000 different rare diseases and collaborates with people living with rare disease, governments, peak bodies, researchers, clinicians and industry.

RVA collaborates with more than 100 consumer-led rare disease groups/organisations and advocates for better outcomes for people living with a rare disease, including 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 delivering the Rare Disease Disability Project for the NDIS through the Peer Support and Capacity Building grant, which includes leading the Rare Disease Disability Network for community-led groups and invited stakeholders.

This submission is informed by contributions from Rare Disease Disability Network members and people living with rare disease disability.

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 first nationally coordinated effort to address rare disease in Australia. RVA is now leading the Action Plan's collaborative implementation on behalf of the rare disease sector.

The Action Plan addresses the NDIS and the often-arbitrary boundary between health and disability, with a strong emphasis on coordinated and integrated care (see Appendix 1).

The Action Plan is built on three principles:

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

References

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Appendix 1 – Disability and the National Strategic Action Plan for Rare Diseases

Specific rare disease 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.

2.1.2.2. Strengthen the National Disability Insurance Agency's response to the nature of disability caused by rare disease that can manifest as chronic, intermittent and often progressive. Initial implementation should prioritise:

- fast tracking access to the NDIS; and
- ensuring NDIS participants can access an appropriate range of respite to meet the needs of families.

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.