



**Community Affairs Legislation Committee Inquiry  
on the National Disability Insurance Scheme Amendment**

**(Getting the NDIS Back on Track No. 1) Bill 2024**

**Rare Voices Australia Submission  
May 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 psychosocial 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 Community Affairs Legislation Committee (the Committee) on behalf of the rare disease sector.

## 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)<sup>1</sup>, the first nationally coordinated effort to address rare diseases in Australia.

The foundation principles of the Action Plan are also at the heart of the challenges facing the National Disability Insurance Scheme (NDIS) and are areas of focus for this Submission:

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

## National Disability Insurance Scheme Amendment Bill 2024

In October 2022, the Australian Government commissioned the NDIS Independent Review (NDIS 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.

In June 2023, RVA was pleased to provide a [detailed submission to the NDIS Review](#)<sup>2</sup> for consideration.

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

In December 2023, the Prime Minister and state and territory governments agreed to an initial response to the final report of the NDIS Review. This included introducing legislation changes in the first half of 2024.

On 27 March 2024, the Australian Government introduced changes to the *NDIS Act 2013* (*NDIS Act*) and the Senate referred the provisions of the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024<sup>4</sup> to the Senate Community Affairs Legislation Committee for inquiry and report by 20 June 2024.

RVA understands that the Bill represents the first tranche of several upcoming amendments to the NDIS Act.

At the time of writing this Submission, neither the Federal nor state and territory governments have provided a formal response to the NDIS Review Recommendations.

## **RVA's Submission**

In preparing this Submission, RVA engaged with our RVA Partners (rare disease groups/organisations) and individuals and families living with a rare disease, including convening a virtual national roundtable. Their observations, concerns, and recommendations are reflected in this Submission.

### **Timing and Transparency**

RVA and the rare disease sector acknowledge the transformative role the NDIS has played in funding and supporting people with a disability in Australia.

RVA supports all efforts that seek to provide an integrated person-centred support model for people living with a rare disease and disability impacts, and equitable access to services, supports, and quality outcomes.

However, RVA, RVA Partner organisations and people living with a rare disease and disability impacts express considerable concern regarding the timing and transparency of this Bill and the broader NDIS Reform Agenda.

The government has not yet responded formally to the NDIS Review Recommendations, yet legislation to amend the NDIS Act is progressing.

The absence of a publicly available Bill Implementation Plan, co-designed with the disability sector, is problematic. The rapid implementation of changes and associated risks during transition periods requires careful management to avoid compromising participant outcomes and safety.

It is urgent that the government co-design and release a transparent engagement and implementation plan to ensure the community and Parliament understand the Bill's vision and intentions and the broader NDIS Reform Agenda.

## Recommendations

- 2. Provide formal acceptance of NDIS Review recommendations**
- 3. Publicly share the Bill Engagement and Implementation Plan with the community and Parliament**

## Importance of Co-Design

The [NDIA Engagement Framework – Strengthening our relationship with the disability community and enabling co-design](#) (v1 March 2022) emphasizes co-design and consultation for significant changes impacting participants' interactions or experiences with the NDIS. However, the Bill's consultation process has been criticised for its lack of inclusivity and transparency.

The Federal Government should provide a NDIS Reform Stakeholder Engagement Plan to allow the sector time to prepare and allocate resources to ensure effective collaboration.

The absence of publicly available economic modelling raises concerns about achieving the targeted cost savings and maintaining comprehensive access to essential disability supports.

Rapid implementation of changes poses risks to participant safety and outcomes, requiring careful management.

## Recommendations

- 4. Develop a detailed Stakeholder Engagement Plan to facilitate preparation and resource allocation within the disability sector**
- 5. Ensure economic modelling is publicly available to address concerns about cost savings and access to supports**

## Scheme Architecture and Legislative Instruments

RVA is concerned that the structure and timing of this legislation pose a major risk in terms of leaving the estimated two million Australians with a rare disease without appropriate support.

- **Foundational and Mainstream Supports**

The proposed legislation introduces an early intervention requirement alongside the existing disability requirement for accessing the NDIS. Early intervention aims to provide support to potentially reduce the need for lifelong NDIS participation by integrating individuals into the mainstream system, including through the proposed 'Foundational

Supports'. However, Foundational Supports have not yet been defined or co-designed with the disability sector.

RVA believes there is a high risk of individuals falling through service gaps between NDIS and mainstream supports, and the yet-to-be-developed 'Foundational Supports'. This risk is further heightened in rural and regional areas, which already face workforce shortages and thin markets in disability support services.

State and territory governments have not made strong commitments to fully fund and implement necessary mainstream service transformations that directly impact people living with a rare disease and disability impacts, such as health and education.

RVA calls for commitments from state and territory governments to ensure foundational supports are co-designed with the disability sector, clearly define the scope of the supports, are adequately funded, and address thin markets.

Legal experts argue that the Applied Principles and Tables of Support (APTOS) tool is not suitable law and should not be linked to the Bill.

Co-design is crucial to prevent service gaps and ensure supports are accessible, equitable, appropriate, and effective for people living with a rare disease and disability impacts.

Other aspects of the Bill that seek to narrow the scope of NDIS supports, transition people with disability off the NDIS, or deny NDIS access require much further clarification to allay the concerns of the disability sector.

More work is required to ensure clear designated responsibilities for disability support across all jurisdictions before changing legislation.

## **Recommendations**

- 6. Secure commitments from state and territory governments to fully fund and implement robust foundational supports before enacting any sections of the Bill**
- 7. Co-design Foundational Supports with the disability sector, including RVA, the national peak body representing an estimated two million Australians living with rare diseases**
- 8. Recognise that low-intensity foundational supports or mainstream services are not appropriate alternatives to the NDIS for individuals living with a rare disease and complex needs**
- 9. Address the legal concerns regarding the APTOS tool and ensure it is not linked to the Bill until it is usable law**
- 10. Ensure the legislation does not inadvertently deny access to necessary NDIS supports based on jurisdictional responsibility**

- **NDIS Rules**

The Bill relegates essential NDIS architecture to legislative instruments (the Rules), risking loss of NDIS integrity and reducing visibility, accountability, and parliamentary oversight.

NDIS Rules are negotiated with states and territory governments, and it is currently unclear how the NDIS Rules will be developed and how co-design with the disability sector will occur.

It is also unclear whether co-design will occur across all NDIS Rules or selected instruments only.

## **Recommendations**

- 11. Table the draft NDIS Rules for transparency and consultation purposes**

- 12. Provide explicit commitment that the disability sector will be actively engaged in co-design of all NDIS Rules**

- **Ministerial determinations**

The Bill maintains current disability requirements but introduces two distinct needs assessment processes: a functional needs assessment, and a support needs assessment.

The Bill currently gives ministerial powers to determine the needs assessment processes in their entirety, and how they convert into a budget. In doing so, RVA notes that the Minister must have regard to the financial sustainability of the NDIS.

RVA accepts that Ministerial determinations are an appropriate mechanism when there are expected changes to processes and practices over time. However, we have concerns regarding the level of transparency and accountability within the current Bill.

RVA is seeking clarification regarding the process of co-design for the Ministerial determinations. We recommend strengthening the determinations to build trust and increase scrutiny by formally requiring that the Minister provide evidence to demonstrate how comprehensive and wide-ranging consultation and co-design with the disability sector has informed the determinations.

We express genuine concern that consideration of the financial sustainability of the NDIS will be used in an unconsidered way to decline or modify approved NDIS supports. This has the potential to lead to unmet needs for people living with a rare disease and disabilities, who often require extensive high-intensity supports.

Needs assessment tools must be developed in consultation with the disability community and experts. These tools must ensure assessments are conducted by qualified health professionals who understand the participant's history and needs and are chosen by the participant.

Tools and models used to determine support packages must be transparent and based on research evidence. All algorithms, assumptions, calculations, benchmarks, and models must be transparent and understandable to participants. Without this, participants may struggle to effectively exercise their review and appeal rights.

The NDIS PACE system is already operationalised with functionality, including budget setting tools and controls, that are available but not yet activated and awaiting legislative changes. These must be tabled for review before arbitrary powers are granted to the Minister (or their delegate).

RVA Partners raised issues with how the NDIS has been capturing and using participant data to date. This includes inaccurate and incomplete participant data, inconsistent coding and recording of participant disabilities, and lack of visibility of multiple conditions and factors.

At a systemic level, it is unclear to RVA how the NDIS has used a decades' worth of data to inform policy reform, especially for NDIS participants living with complex rare disease.

RVA recommends significant improvements to the quality and robustness of NDIS data management systems, including coding of NDIS participants with a rare disease and the development of a Rare Disease Disability Dashboard. Improved data analysis may also enable the development of evidence-based practice guidance for NDIS staff and participants.

## **Recommendations**

- 13. The assessment and budget-setting processes must be co-designed with the disability community including RVA, to ensure fairness and equity**
- 14. Include transparency principles in the legislation for the budget-setting method to ensure oversight and community trust, including how financial sustainability will be measured against the needs of the participant**
- 15. Table for review the proposed criteria, algorithms and calculation methodology for budgets for sector scrutiny and consultation prior to approving this legislation**
- 16. Develop needs assessment tools and budget-setting methods in genuine co-design with the disability community, including RVA to avoid pitfalls of previous NDIS reforms**
- 17. Ensure needs assessments are conducted by qualified health professionals who understand the participant's history and needs**
- 18. Ensure flexible budgets are sufficient to meet the current and emerging needs of participants, with particular consideration for the rare disease cohort**
- 19. Allow sufficient time for deliberative and consultative engagement and co-design where appropriate by amending the Bill implementation timeline**

## **20. Overhaul NDIS data management systems to improve the quality of data and to better inform evidence-based practice and policy reform.**

### **Funding Periods and ‘Intraplan Inflation’**

The Bill proposes the introduction of flexible funding and funding for stated supports, with the method for determining budgets set by the Minister. The Bill increases the powers of the Minister and NDIS CEO to vary the fund management category and funds access for a NDIS participant where they believe that inappropriate funds utilisation is occurring.

Current NDIS processes do not afford the NDIS participant principles of natural justice and the right of reply to allegations of misuse of funds. This must be included in the Bill.

The Bill introduces funding periods to manage 'intraplan inflation,' releasing total funding in stages over the plan period, and potentially capping monthly utilisation for some participants to manage risk of budget overspend.

Reasonable and necessary budgets must consider the episodic, fluctuating, and progressive nature of several rare disease conditions, and ensure that there is provision built into the budget to ensure they are responsive to emerging needs.

RVA is incredibly concerned that the government is targeting ‘intraplan inflation’ without having robust policies and procedures in place to respond adequately to this cohort.

The high rate of reviews and appeals in recent times is an indicator that the NDIS may not have been adequately building plan funding to meet the reasonable and necessary needs of the participant. This approach requires careful implementation to ensure plan budgets are well crafted from the outset to limit avoidable and costly reviews, prevent gaps in support, and ensure participants' needs are consistently met throughout the plan period.

RVA believes that methods for setting budgets should be transparent, co-designed with the disability sector, and subject to regular parliamentary oversight.

RVA is concerned that the Bill links budget funding to the impairments accepted by the NDIS at the time of access, potentially disadvantaging participants with complex, acquired, and progressive disabilities that may change over time.

People living with a rare disease can have progressive conditions and degenerative disorders, requiring a system that is flexible to reflect rapidly changing levels of function. In some cases, the trajectory of a condition is unknown.

The findings of the NDIS Review were that there was an intention to resolve the issue regarding whether supports could only be funded for so-called ‘primary’ disability or could include funding for ‘secondary’ disability. RVA had understood that this distinction would be removed with supports determined on a holistic assessment of function and need, thereby

catering for people with multiple disabilities, as is often the case for people living with a rare disease.

RVA believes that the addition of new Bill criteria could inappropriately restrict the NDIS from responding to the changing impacts of people living with a rare disease and result in a lack of appropriately funded essential supports.

## **Recommendations**

- 21. Include a 'no disadvantage' provision when participants move from the old framework budget to the new framework budget**
- 22. Embed the principles of Natural Justice for participants when funds utilisation is questioned by the NDIS**
- 23. The method for setting budgets should be transparent, co-designed with the disability sector, including RVA, and subject to regular parliamentary oversight**
- 24. Plan budgets must include consideration of NDIS participants with fluctuating, episodic, progressive, and/or degenerative conditions and provide flexible budget access throughout the life of the NDIS plan**
- 25. Support needs must reflect current functional impacts, without being limited to impairments identified at the time of access**

## **NDIS Supports**

The new definition of 'NDIS Support' based on aspects of the United Nations Conventions of the Rights of Persons with Disability (CRPD) seeks to narrow the scope of NDIS funding and may have unintended consequences that exclude or limit access to essential disability supports, equipment, and services.

Concerns include the potential exclusion of:

- Certain types of assistive technology, including Augmentative and Alternative Communication (AAC) devices, tools, and software or smart technology AT solutions that enable increased autonomy and independence
- Disability-related health supports – this must be clearly defined to ensure continued provision of NDIS-funded supports as per current arrangements. Delineation issues between NDIS and health that leave people with a rare disease vulnerable and without essential, life-sustaining services and provisions, cannot occur
- Personal care support
- Economic/employment and recreational supports
- Does not mention economic/employment and recreational supports
- Supports fostering independence and increased dignity, safety, and respect for people with disability.

RVA finds the use of the term 'health service' problematic given the division between NDIS and health service provision. The current term, 'disability-related health supports' describes this accurately and clearly identifies these supports as NDIS Supports.

Furthermore, rehabilitation services have historically been regarded as the purview of the health departments; the scope and responsibility for habilitation and rehabilitation services require further definition.

RVA supports rules that clearly and specifically define which supports will and will not be funded by the NDIS. This includes increased specificity about which supports are NDIS-funded and which will be state/territory funded (e.g. as foundational supports).

RVA is aware that the current or 'old framework plans' can be revisited and narrowed based on the NDIS supports definition and seeks urgent information regarding the impact on participants.

## **Recommendations**

- 26. Simplify and clarify the definition of the general categories or types of supports included in the concept of NDIS supports**
- 27. Ensure the definition reflects the full scope of the UNCRPD to avoid confusion and ensure comprehensive support**
- 28. Explain how changes to the definition of NDIS supports will be applied, including to current or 'old framework' plans and funds utilisation**

## **Classes of Participants**

When discussing NDIS supports, the Bill refers to "supports, or classes of supports" throughout the document. Classes of supports are interpreted to mean that there will be tailored supports and rules around these supports that apply to certain disability types.

RVA is concerned about the potential for a classification system to segregate participants based on identifiable characteristics. This system could lead to potential discrimination and policy segregation.

The classification system's specifics and its implications for participant equality and equity are not clearly explained in the Bill, raising numerous questions for the disability sector.

RVA has consistently and repeatedly engaged with the government regarding people living with a rare disease and disability impacts, specifically regarding the multiple disabilities that can occur across many functional domains. Attempts to group NDIS participants with rare disease into arbitrary classes is extremely problematic.

## Recommendations

- 29. Ensure the Bill provides clear definitions and explanations for the proposed classification system, detailing how it will be applied and its implications for participants**
- 30. Co-design the classification system with input from the disability sector, including organisations representing individuals with rare diseases and RVA as the national peak body for Australians living with a rare disease. This engagement will ensure the system reflects the diverse and complex needs of all participants**
- 31. Implement measures to monitor and address any discriminatory practices arising from the classification system. Guarantee that all participants receive equitable support tailored to their specific needs, regardless of their disability type**

## Rights to Reassessment and Review

Under the proposed Bill, participants will have the right to seek review of the statement of participant supports, which includes the reasonable and necessary budget. However, participants will not have a right to seek a review of some of the new processes the Bill creates, either internally by the National Disability Insurance Agency (NDIA) or externally by a Tribunal.

Given the centrality of a needs assessment report in the subsequent process to determine a reasonable and necessary budget, the right to review must be made explicit in the legislation.

The needs assessment and budget-setting processes must be co-designed with RVA and the disability community to ensure fairness and equity. Transparent development of these processes ensures participants can understand and appeal decisions.

The Bill must include explicit mechanisms for NDIS participants to appeal, contest, and request a review of all determinations and decisions.

The current planning, review, and appeal processes are often experienced as traumatic and stressful for participants, leading to negative physical, emotional, mental, and financial impacts. There is a critical need for alternative, trauma-informed models of review and appeal.

## Recommendations

- 32. Incorporate provisions for participants to review and clarify draft reports, including needs and support assessments, and to request new assessments if required**
- 33. Clarify participants' rights to appeal decisions related to needs assessments and budget determinations**

- 34. Clarify the role of the Administrative Appeals Tribunal and the scope of matters that can be reviewed and appealed**
- 35. Train NDIA decision-makers and representatives (including legal professionals) in disability and trauma-informed communication**
- 36. Extensively co-design and trial new assessment processes to ensure they are equitable and effective. Incorporate feedback from participants, treating professionals, and allied health experts in the design and implementation of assessments.**

## Conclusion

RVA and RVA Partners recognise the necessity and significance of the NDIS Reform to ensure an equitable and sustainable NDIS. However, given the raft of legislative changes that the government is proposing and the scope of the reform agenda, we believe it is imperative to take the time to ensure the human rights and needs of people with disability are preserved and enshrined in any changes.

We believe an appropriate Bill should include constraints to Ministerial and NDIS CEO or delegate powers. This would include a requirement to co-design with the disability sector including RVA, increased parliamentary oversight, improved government transparency and accountability. We believe this is necessary to build trust with the disability community.

RVA welcomes the opportunity to actively engage in all areas of the NDIS Reform agenda and to assist the government through the co-design of robust and appropriate legislation and policy that delivers quality outcomes for people with disability.

## References

1. 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 May 2024].
2. Rare Voices Australia Submission to the National Disability Insurance Scheme Review. June 2023. Available from: <https://www.ndisreview.gov.au/submissions/sub-c2n4-001914> [Accessed May 2024].
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 May 2024].
4. Commonwealth of Australia, Department of Social Services. National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024. May 2024. Available from: [Changes to the NDIS Act | Department of Social Services, Australian Government \(dss.gov.au\)](https://www.dss.gov.au/changes-to-the-ndis-act) [Accessed May 2024].