



Department of Health, Disability and Ageing

**National Disability Insurance Scheme (NDIS)
New Framework Planning Rules**

October 2026

Rare Voices Australia Submission

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Introduction

Rare Voices Australia (RVA) welcomes the opportunity to provide feedback on the Department of Health, Disability and Ageing's consultation on the remaining National Disability Insurance Scheme (NDIS) New Framework Planning Rules (the Rules).

RVA previously provided a detailed submission to the Department's March 2026 consultation on the [NDIS New Framework Planning reforms](#). The recommendations made in that submission remain relevant and should be considered alongside this response. This submission focuses only on issues arising from the additional information released since March 2026 regarding support needs assessments, budget methodologies and planning processes.

Rare disease disability presents unique challenges for disability assessment and planning. While individual rare diseases are uncommon, approximately two million Australians live with a rare disease, including an **estimated 100,000 NDIS participants who experience severe or profound rare disease disability impacts**.

Rare disease disability is often characterised by complex, multisystem, progressive, degenerative, episodic or fluctuating impacts that are difficult to capture through standardised assessment, planning and funding approaches. Effective planning processes must therefore be sufficiently flexible and responsive to recognise the cumulative, intersecting and changing nature of support needs experienced by people living with rare disease disability.

RVA welcomes the additional planning information and alignment of the Support Needs Assessment with principles in the International Classification of Functioning, Disability and Health (ICF). However, further detail and safeguards are needed to ensure equitable outcomes for people with rare disease disability.

RVA is concerned about how support needs assessments will be translated into budgets, access to targeted assessments where specialist evidence is difficult to obtain, the treatment of informal and community supports, and whether New Framework Planning processes will adequately capture the complex nature of rare disease disability.

Recommendations

Recommendation 1

Release exposure drafts of the Planning Rules and Budget Methodology Rules before implementation, including worked examples demonstrating how people with progressive, fluctuating and multisystem rare disease disability will be assessed and funded.

Recommendation 2

Require draft assessment reports to be provided to NDIS participants for review and correction before budgeting, ensuring rare disease complexity, cumulative impacts and specialist evidence are accurately reflected.

Recommendation 3

The National Disability Insurance Agency (NDIA) should fund and facilitate access to medical and allied health providers needed to obtain targeted assessment evidence, particularly for participants living in regional, rural and remote areas.

Recommendation 4

Provide interim plans and budgets where assessment evidence cannot be obtained within planning timeframes, with funding reviewed once outstanding evidence becomes available.

Recommendation 5

Prohibit the use of an informal supports offset as a budget-reduction mechanism and recognise the significant levels of unpaid support rare disease caregivers and families provide because formal supports are unavailable, inadequate or difficult to access.

Recommendation 6

Maintain flexible community participation funding that reflects individual support intensity and disability complexity for people with rare disease disability, rather than relying on standard default allocations.

Response to Consultation Questions

Support Needs Assessment Rules

Q. What parts of the support needs assessment process need more explanation?

- **Translation of Assessment Outcomes into Support Categories**

The consultation paper explains the assessment domains and support categories but not how assessment findings will determine support categories or funding.

Many rare diseases affect multiple body systems and result in complex, interacting neurological, respiratory, metabolic, behavioural and communication impacts. The proposed process does not explain how assessors will account for progressive or fluctuating conditions, or how the cumulative impact of multiple impairments will be assessed across different areas of functioning.

Without this information, participants cannot understand how assessment findings will influence support categories or funding decisions.

- **Targeted Assessments**

The proposed Rules do not clearly explain when targeted assessments will be required or how participants will access them if the necessary evidence is unavailable. The consultation paper appears to assume that participants already have the evidence needed for a targeted assessment when often they do not.

People with rare disease disability may struggle to obtain specialist reports because of long waiting times, workforce shortages, and limited expertise/data in their condition. The Rules should require the NDIA to fund and help participants access any medical or allied health evidence needed. Participants should not be disadvantaged because reports are difficult, costly or unreasonable to obtain.

The Rules should also state whether assessors can start a targeted assessment when a previously unidentified need becomes clear during the assessment process.

The Rules also need to explain how planning will proceed when several targeted assessments are required. People with rare disease disability may need assessments across assistive technology, disability-related health, home and living, communication, behaviour and home modifications. These assessments may take considerable time to obtain. It is unclear whether a support needs assessment, budget or plan can be finalised while targeted assessment evidence is still being gathered.

Participants should not face delays, funding uncertainty or poorer outcomes because qualified professionals are unavailable or evidence cannot be obtained within planning

timeframes. The NDIA should explain if commissioned services, telehealth or specialist assessment panels will be provided to support equitable access, particularly in regional, rural and remote areas.

If a targeted assessment cannot be completed on time, the participant should receive an interim plan or budget based on the best available evidence. Funding should be reviewed and adjusted when the remaining information becomes available. This would maintain timely access to necessary supports while evidence is gathered.

Q. Do you have feedback on the Support Needs Assessment report?

Participants should be able to review the draft support needs assessment report and correct factual errors before it is used to calculate their budget.

The Rules should require a draft report stage, give participants clear review rights, and set out a process for correcting factual errors.

Q. When should a replacement assessment occur?

RVA supports replacement support needs assessments where significant factual errors are identified, relevant evidence was not considered, there are changes to informal supports, living/caring arrangements or a significant life transition, or progressive deterioration means the assessment no longer accurately reflects support needs.

Budget Method Rules

Q. What information would help participants understand how a budget is calculated?

The detailed budget methodology has not been released. RVA continues to call for exposure drafts of the budget rules, with clear explanations of how assessment findings are converted into budgets.

Participants need to know how evidence is weighted, how multiple impairments and their combined impact are assessed, how personal and environmental circumstances are considered, and where delegates may use discretion. This information is essential for participants to understand how their evidence affects funding decisions and to trust that the process is fair and consistent.

- **Informal support offsets**

Informal support should complement, not replace, reasonable and necessary disability supports. RVA is concerned about the proposed ‘**informal supports offset**’ in In-Home and Community Supports funding calculations. Many rare disease families already provide extraordinary levels of unpaid care over long periods, often because formal supports are unavailable, inadequate or inaccessible.

RVA recommends that participant budgets should not be reduced based on presumed informal support availability. Informal supports should only be considered where participants choose to rely on them, taking into account carer sustainability and wellbeing. Any assumptions regarding informal supports must be transparent and reviewable.

- **Community participation funding**

The proposal would include community supports funding within the In-Home and Community Supports (IHCS) budget and give participants a **default community supports allocation** rather than an amount set through delegate discretion.

A standard allocation may not reflect the wide range of support needs among people with rare disease disability. Community participation may require continuous one-to-one support, specialised communication or behaviour supports, or disability-related health supports. These needs can create much higher participation costs. A standard allocation that does not account for support intensity and individual circumstances could lead to inequitable outcomes.

The consultation paper does not explain how the default amount will be calculated, whether assessment outcomes will inform it, or how higher support needs will be recognised.

The Rules should explain how communication and behaviour support needs, living circumstances, travel requirements and geographic location will affect community participation funding.

Conclusion

RVA welcomes ongoing engagement in the development and implementation of the final Rules to ensure they are transparent, flexible and responsive to the complex, diverse and evolving impacts of rare disease disability. The recommendations outlined in this submission will provide necessary safeguards, promote consistency in planning decisions, and support equitable access to NDIS supports for people living with rare disease disability.

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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 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](#), which continues until December 2026. 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 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 people¹. 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 impacted¹. 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."^{1,2} **This includes the estimated 100,000 NDIS participants with severe and profound rare disease disability impacts.**

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.

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.

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)³, the first nationally coordinated effort to address rare diseases in Australia. RVA is now working in partnership with stakeholders to support the collaborative implementation of the Action Plan, recognising that implementation is the shared responsibility of the entire 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.

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

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

Implementation

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

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

Implementation

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

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

References

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3. Commonwealth of Australia. Department of 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 October 2026]