National Disability Insurance Scheme (NDIS) New Framework Planning Rules

March 2026

Rare Voices Australia Submission

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. 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 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

Nearly all of the estimated 2 million Australians living 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.**

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)[1], 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.

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.

Rare Voices Australia's Submission

Thank you for the opportunity to contribute to the Department of Health, Disability and Ageing (DHDA) consultation on the NDIS New Framework Planning Rules.

While RVA supports the intent to deliver a fairer, more transparent and sustainable planning process; the material released to date **does not provide the detail required for meaningful consultation.**

- Critical information has not yet been provided; including the budget methodology, evidence weighting rules, assessor safeguards, limits on stated supports, and practical review protections.
- The draft rules do not yet incorporate sufficient safeguards for people with progressive, degenerative, episodic and fluctuating conditions, including many rare diseases.
- There is no published evidence of reliability, equity or predictive adequacy of the NDIS-customised Support Needs Assessment (SNA) tool.

RVA recommends publishing Exposure Drafts of all relevant rules, validating assessment tools before use, and embedding stronger safeguards.

Reform must be transparent, evidence based and procedurally fair. Ensuring participants can see how their evidence translates into their budget is essential to trust, equity and the long-term integrity of the NDIS.

RVA advocates for NDIS rules and a New Planning Framework that deliver the following for participants with rare disease disability:

- Person-centred
- Value for money
- Equity of outcomes
- A sustainable and capable disability workforce.

Recommendations

1. **Publish Exposure Drafts for meaningful consultation**
   - Release full Exposure Drafts of the Planning Rules and the Budget Methodology Rules to enable genuine consultation and parliamentary scrutiny.
   - Provide a plain language guide to the budget method with steps, weightings and worked examples that reflect rare disease disability, including progressive, fluctuating and multi system needs.
2. **Pause implementation until safeguards are proven**
   - Pause the national rollout of new assessments and planning rules until Exposure Drafts are published, assessed, and improved with stakeholder input, real world trial results are available and rare disease disability safeguards are in place.
3. **Notice of Impairments (NOI)**
   - Prepare a plain language NOI, that clearly explains what impairment categories are, how a person’s impairment category is decided, how categories can be updated, and how to request a change.
   - Recognise that people living with rare disease disability often experience multiple impairments that don’t fit neatly into one category. Establish a dedicated “multiple impairments” category so these combined impacts are properly reflected and supported.
   - Publish the full NDIS impairment category mapping to known conditions, to ensure transparency, consistency and fairness.
   - Impose a mandatory duty requiring the CEO to correct impairment information whenever inaccuracies are identified. Corrections must include written reasons and maintain review rights.
   - Require the CEO to proactively update a participant’s NOIs when new information becomes available, without needing a participant to apply for a plan variation.
4. **Validate the Support Needs Assessment (SNA)**
   - Publish independent, peer reviewed validation and equity evidence, including real-world trial results, demonstrating the reliability and predictive adequacy of the SNA across cohorts with rare, multisystem, progressive, episodic, intellectual and communication disabilities, and complex behaviours.
   - Publish clear triggers and timeframes for targeted assessments, outline how specialist input will be secured, and ensure interim supports are provided while participants are waiting.

5. **Training and qualifications of NDIS assessors and decision makers in rare disease disability**
    - Publish NDIS assessor competency standards and accreditation (including trauma informed, neurodiversity, rare/complex, cultural capability standards) and minimum qualification/registration expectations.
    - Require mandatory, codesigned training (with RVA as the national peak body and the rare disease disability community) on rare, progressive/degenerative, multi system and communication-related needs.
6. **Remove assumptions about informal supports**
    - Do not reduce budgets based on presumed availability of unpaid informal or peer supports. Where participants choose to use informal supports, apply clear consent and sustainability tests, recognising that rare disease caregiving often carries high and variable burden.
7. **Require full consideration of treating professional evidence**
    - Assessors and delegates must be required to fully consider treating specialist and allied health evidence, particularly where published research is limited or non-existent for rare, multisystem or undiagnosed conditions.
    - Recognise functional and lived experience evidence and ensure participants without access to specialist services are not disadvantaged.
    - Where the National Disability Insurance Agency (NDIA) departs from treating professional evidence, it must provide written reasons that directly address that evidence and explain how it was considered or weighted.
8. **Mandatory draft assessment report stage**
    - Guarantee participants the right to review and correct a draft SNA report before it informs budgeting.
9. **Funding periods**
    - Funding periods must reflect real spending patterns, particularly for people with episodic or progressive needs, and allow for rapid intra-plan rebalancing through a simple variation process that does not trigger a full reassessment.
10. **Narrow the grounds for “stated” supports and restrictions**
    - Limit the use of stated supports and restrictions to situations of genuine safeguarding/integrity risk and provide a clear definition of “significant integrity risks”.

- Protect people's access to short-term respite, clinically needed consumables, and replacement assistive technology (AT) by ensuring these supports are **not** turned into stated supports

11. Strengthen review rights to correct unsafe underfunding

- Enable the Administrative Review Tribunal (ART) to vary total funding where method or assessment errors lead to unsafe underfunding, or to mandate expedited reassessment and to provide interim funded supports during disputes, which is particularly important for high-risk rare disease disability support needs.

12. Address thin market risks for rare disease cohorts

- Establish quality controlled thin market arrangements only where necessary and include the right for participants to opt out and access funded alternatives, recognising that rare disease disability expertise may be required.
- Offer implementation meetings to participants by default, especially for high-risk rare cohorts.

Detailed Feedback by Planning Step

The following information has been prepared in response to the NDIS New Framework Planning consultation resources provided by the DHDA.

Step 1 — Preparing for a Support Needs Assessment (SNA)

RVA welcomes the intent to improve clarity and support participants to prepare for planning. However, stronger safeguards and clear, enforceable duties are required to ensure accuracy, fairness and accountability during this early stage of the planning pathway.

1. **Clarity and accuracy of the NOI**

The NOI must use plain language to explain impairment categories, how categories are determined, how updates occur, and how participants can request a variation.

Many participants living with rare disease disability experience **multiple or compounding impairments** that do not fit neatly within a single impairment category.

RVA recommends establishing a "**multiple impairments" category** within the rules to better reflect cumulative impacts.

2. **Publish impairment category mapping to improve transparency and consistency**

RVA recommends that the NDIA publish the **full impairment category mapping** used to assign categories for known conditions.

The NDIA should publicly explain how impairment categories are determined for **rare, ultra-rare, progressive, episodic and undiagnosed** conditions, including:

- how **multi-system impacts** are mapped across categories
- how **functional evidence** is treated when there is no formal diagnosis
- how **condition and clinical uncertainty** is handled
- how **emerging evidence** (e.g., **genomic results**) influences categorisation.

3. **Define what constitutes "good evidence"**

The draft rules refer to "clinical, diagnostic or other evidence" without defining these terms.

RVA recommends the NDIA publish an **evidence standard** that accepts evidence from a wide range of clinical professionals, including those familiar with rare and undiagnosed conditions. The evidence standard should recognise **functional and lived experience evidence** (e.g., documented deterioration by support workers, allied health or carers) and must not disadvantage people who do not have access to specialists or diagnostic testing.

4. Replace discretionary variation powers with enforceable duties

Under the current drafting, the CEO *may* vary a NOI, even where clear errors or new clinical evidence exist. The framework provides procedural pathways for variation, but **no enforceable duty** on the CEO to correct inaccurate impairment information.

Without an enforceable duty, participants, especially individuals with complex or progressive conditions, may have **known inaccurate records** that directly influence the SNA, plan budgets and application of the budget method. This places the administrative burden on people with disability to correct the NDIA's own records.

RVA recommends a **mandatory correction duty**:

> *When the CEO becomes aware, through any source, of inaccurate or outdated impairment information, the CEO must vary the Notice and issue written reasons within prescribed timeframes.*

Awareness should include diagnostic updates, SNA outputs, eligibility reassessment findings or other credible information. Decisions must outline the evidence considered, reasons for accepting or rejecting clinical evidence, and how interacting impairments were assessed. All decisions remain reviewable under the NDIS Act.

5. Proactive review obligations

Participants should not bear responsibility for identifying or correcting NDIA errors.

RVA recommends that the CEO is required to **proactively review and correct** NOI when new information is received, **without requiring a participant application for plan variation**.

6. Preparation and planning

To reduce uncertainty and support readiness for the SNA, the NDIA should:

- publish a **transition schedule window** (month/quarter) by participant cohorts
- set a **minimum notice period** before a SNA is scheduled
- allow flexibility to defer or reschedule due to hospitalisation, crisis or complex transitions.

Step 2 — Support Needs Assessment (SNA)

The SNA brings together:

- a NDIS customised core tool based on version 6 of the Instrument for the Classification and Assessment of Support Needs (**ICAN**)
- a Personal & Environmental Circumstances Questionnaire (PECQ)
- a set of targeted assessment modules (e.g., Assistive Technology, communication, behaviour support, home/vehicle modifications).

While the I-CAN is administered by trained and accredited allied health and behaviour support practitioners, the SNA is administered by the NDIA assessor workforce. As this is a novel integration of adapted tools, participants need assurance that what is measured is valid, equitable and safely translated into budgets.

There is no clear explanation of how the SNA will consider multiple impairments in combination, how health versus disability distinctions will be resolved, or how fluctuating/episodic conditions will be represented over time. The SNA must recognise therapies that maintain function or prevent decline, not only therapies that improve function.

The current approach risks a **point-in-time snapshot** that describes what a person can do in a single session rather than what supports are required for participation, safety and dignity over time. This may create unsafe funding and inaccurate SNAs for rare disease disability cohorts, where invisibility, variability and clinical uncertainty are common.

1. **Validation and equity evidence**

At present, there is no published, independent validation demonstrating reliability, validity or predictive adequacy of the customised I-CAN v6, the PECQ or the targeted modules for accurately assessing support needs for participants with intensive, complex and cumulative impairments, or for the purpose of determining budgets.

RVA recommends that, before national implementation, the NDIA, the University of Melbourne and Centre for Disability Studies publishes peer reviewed validation and equity evidence across rare, progressive, degenerative and fluctuating conditions, and across First Nations, culturally and linguistically diverse (CALD), LGBTQIA+ and remote cohorts. The Action Plan identifies Aboriginal and Torres Strait Islander people and people from CALD communities as priority populations.

2. **Evidence use and weighting—lived and treating knowledge must count**

Allied health and treating specialists bring longitudinal knowledge of trajectory, environmental impacts and support intensity for rare disease disability.

RVA recommends that treating specialist and allied health evidence must be considered and weighed and where the NDIA departs from that evidence, it must provide written reasons that directly addresses the decision to do so.

3. **Participant voice, access and safety**

RVA strongly advocates for a person-centred approach. For example, assessments must be organised with the participant, and guarantee choice of mode (face-to-face, online, phone) and venue accessibility, and publish a service standard for session length ranges and breaks.

The SNA should mandate collection of goals and preferences and require the report to explicitly link needs to goals and environment.

4. **Assessor capability and quality**

A safe, equitable SNA depends on assessor competence. RVA recommends the NDIA publish assessor competency standards and accreditation requirements, that include trauma-informed practice, cultural capability, neurodiversity competence, rare/complex/episodic conditions, and specify minimum qualifications/registrations.

5. **Process fairness and time-bound rights**

Participants must be given the chance to fix mistakes before a SNA shapes their budget. RVA continues to advocate that the rules must include the right to a draft report, and that there is a defined process to correct factual errors or omissions before the SNA is provided to the NDIA delegate for budgeting.

6. **Operational clarity for targeted assessments**

Participants should not be left waiting without supports while completing subsequent targeted assessment modules or accessing NDIA-required expertise.

RVA recommends that the rules ensure the provision of interim supports while waiting for additional targeted assessments to be completed. The NDIA should publish clear criteria and triggers for targeted assessment modules, timeframes for assessment completion, and how specialist input will be secured, particularly in thin markets such as rare disease disability.

7. **Group homes, supported living and multi-person rare disease households**

RVA recommends that the rules must specify how assessments will be adapted and tailored for shared living environments, including group homes, independent living and households where more than one person has a rare disease disability. This must also **consider rare caregivers who hold dual or multiple roles,** including caregivers who also have the same or a different rare condition.

Step 3 — Building a Plan

1. **Budget method**

The rules require the NDIA to use SNA information and a technical calculation to determine funding, but the method is not published. RVA recommends publishing the plain English budget method with worked examples including progressive and fluctuating trajectories, and adjustments to intensity and disability-related health needs.

It is essential that participants be provided with the step-by-step calculation logic for how the evidence is translating to funding in a plan, including inputs, evidence and assessment weightings, assumptions, adjustments and safeguards.

RVA recognises the high and variable burden in rare caregiving and the risks of burnout and breakdown. RVA recommends that budgets must **not** be reduced based on presumed availability of informal family or peer supports. Where a participant **chooses** to rely on informal supports, the rules should apply **clear consent and risk assessments and carer sustainability tests**.

2. **Funding periods**

Funding periods can help structure supports over time, but they must be designed around real spending patterns, particularly for episodic and progressive needs.

Planners should be required to document intensity rationales (e.g., flares, hospitalisations, transitions), and the framework should enable rapid intra-plan rebalancing when allocations are mistimed or incorrect through a simple variation that does not trigger a full reassessment.

3. **Stated supports, restrictions and requirements**

While the Spending Rules allow stated supports and restrictions, the **current breadth of grounds** may create unnecessary risk for people living with rare disease disability. For example, individuals who have clinically essential consumables and disability-related health

supports/assistive technology must not be made “stated.” Inability to access these supports can result in personal harm and preventable hospitalisation.

Short term respite must stay flexible to ensure carers of people with rare diseases can access respite aligned with fluctuating support needs, rather than being locked into a stated support that limits provider choice and responsiveness.

RVA is concerned that the CEO may place restrictions on participants if they have not complied with the NDIS supports rules or spending in accordance with any of their NDIS plans, including plans approved **before NDIS rule changes that became effective on 3 October 2024**. Participants should not be subject to retrospective rules or reinterpretations that alter decisions made under the framework that applied at the time. The planning framework must include **non-retrospectivity**, clear transitional arrangements, and participant level explanations of which ruleset applies to their plan and why.

RVA recommends that restrictions should be **strictly limited to genuine safeguarding and that “significant integrity risks”** are precisely defined in the rules.

Step 4 — Using a Plan

Implementation is a critical point in the planning pathway for people living with rare, progressive, degenerative, episodic or multisystem conditions. For many participants, the risks arise after a plan is approved, when supports are not available, when transitions are unstable, or when complexity requires more active and timely responses from the NDIA. Strong, proactive implementation safeguards are therefore essential.

1. Implementation

RVA recommends that implementation meetings be mandatory and offered by default on an opt out basis to ensure high-risk participants do not fall through the system gaps. This is especially the case for participants with rapidly progressive conditions, or complex multisystem rare disease disability.

2. Variations and thin markets

Where thin markets prevent access to required supports, participants must not be disadvantaged by unspent funds. Participants with rare disease disability frequently encounter limited specialist services and supports require this safeguard to avoid unintentional reductions in future budgets.

Step 5 - Reviews and appeals

The review pathway remains central to fairness in the NDIS. Under the new framework, reviews will focus on whether the **SNA** and **budget method** were applied correctly. However, RVA is concerned that reviewers may lack the power to correct **total funding amounts**, even when method or assessment errors result in **unsafe underfunding**. For people with progressive, degenerative, episodic and fluctuating rare conditions, delays in fixing errors can result in rapid deterioration, crisis or hospitalisation.

RVA strongly recommends preserving participants' existing rights to **internal review** and **ART** review, with **published indicative timeframes** to support transparency and predictability. Budget decisions must remain **reviewable on their merits**; internal review alone is insufficient, as it requires the same agency to correct its own decision.

RVA recommends a clear, accessible remedy pathway with **interim funding protections** during disputes. Essential supports should continue while reviews are underway, especially where there is risk to **safety, health or housing stability**. Review pathways must avoid creating **assessment loops**, where the default response is repeated assessment rather than genuine consideration of participant evidence and correction of outcomes.

Conclusion

The New Framework Planning model has the potential to deliver more consistent, and sustainable models for planning. However, without budget method transparency, validated assessment tools, strong safeguards for variability, and review mechanisms that can correct underfunding, many participants with rare, progressive, degenerative, episodic, fluctuating or undiagnosed conditions will remain at risk.

RVA urges the DHDA to adopt the recommendations in this submission and welcomes all opportunities for continued collaboration, including support for SNA validation, assessor capability training and development, and thin market design.

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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.

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 March 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 March 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 March 2026]