



Department of Social Services

**National Disability Insurance Scheme (NDIS)
Supports Rules**

Rare Voices Australia Submission

July 2025

About Rare Voices Australia

Background

Rare Voices Australia (RVA) welcomes the opportunity to contribute to the Department of Social Services' (DSS) consultation on the National Disability Insurance Scheme (NDIS) Supports rules (NDIS Supports rules).

RVA is the national peak body for Australians living with a rare disease. Nearly all of the estimated 2 million Australians living with a rare disease experience long-term impacts daily – impacts that meet the Australian Government's definition of a disability^{1,2}. RVA advocates for the best outcomes for Australians living with a rare disease, including the estimated 100,000 NDIS participants whose disability support needs are shaped by rare, complex, and often progressive conditions. RVA works with over 100 RVA Partners (rare disease groups/organisations), including several groups/organisations that represent communities with the most complex and intensive rare disease disabilities.

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 diseases in Australia.

RVA is a member of the NDIS Neurodegenerative, Palliative Care and Rare Disease Advisory Group and has formally contributed to the Co-Design Working Groups, consistently raising the concerns and disability support needs of the rare disease disability community.

RVA is pleased to be leading the Rare Disease Disability Project (the Project) which is being delivered through the NDIS [Peer Support and Capacity Building grant](#). This exciting, first-of-its kind 2-year project will conclude in December 2026 with the delivery of the *Rare Disease Disability Toolkit*. The Project includes virtual peer support sessions for people living with rare disease disability impacts and their families and caregivers. It is being guided by a Stakeholder Reference Group comprising people with lived experience of rare disease disability and diverse representation from priority populations (Aboriginal and Torres Strait Islander people; culturally and linguistically diverse communities; people living in regional, rural and remote areas; and other groups).

The Project includes the RVA-led Rare Disease Disability Network (RDDN), a peer support and capacity building network with more than 30 rare disease community-led groups/organisations. The RDDN was pleased to directly engage with DSS on the NDIS Supports Rules during this consultation period.

NDIS Supports Rules Consultation

In August 2024, RVA made a detailed submission to the consultation on the Draft NDIS Supports rules. The submission is available on [RVA's website](#). While some of our recommendations were incorporated into the transition NDIS Support rules introduced on 3 October 2024, many of the key issues continue to be areas of concern nearly 12 months on.

This submission highlights these ongoing challenges and is informed by feedback received from people living with rare disease disability, their families and caregivers, and RVA Partner groups/organisations.

The NDIS has been transformative for many, but its continued success depends on a system that is transparent, flexible, and responsive to the diverse realities of disability. It is critical that the NDIS Supports rules, and the operational procedures and guidance material that support the day-to-day application of the rules, reflects the complexity, diversity, and constantly evolving needs of the rare disease disability cohort.

Broader Sector Reform

The change to the NDIS Supports rules is occurring alongside several other NDIS reforms, creating a complex and stressful environment for participants. One major change was the introduction on 1 January 2025 of impairment notices that now categorise participants based on the functional impairments that make them eligible.

Under the updated legislation, supports funded by the NDIS must now “address needs arising from an impairment in relation to which the participant meets the disability or early intervention requirements.”

This means:

- Participants must understand their approved impairment categories.
- They must ensure that any support they seek is directly linked to those impairments.
- There is concern that the National Disability Insurance Agency (NDIA) may withhold payments, raise debts, or change funds management if supports fall outside these categories.

Due to this uncertainty, many participants are avoiding necessary services and supports out of fear of penalties, sanctions, or debt. This potentially undermines the core principles of the NDIS: choice, control, and inclusion.

Key Issues and Recommendations

The NDIS Supports rules require clarification, improved implementation and more consistent application to ensure that the rights and needs of NDIS participants living with rare disease disability are protected. RVA offers the following summary of key issues and recommendations.

1.1. General Principles

The National Strategic Action Plan for Rare Diseases (2020)³ (the Action Plan) highlights the need to strengthen the National Disability Insurance Agency's response to the nature of disability caused by rare disease. RVA understands that the DSS will not implement a principles-based framework to the NDIS Supports rules and will retain the prescriptive lists of supports due to legislative requirements. While we are disappointed with this decision, we strongly urge the government to embed the following guiding principles, including the foundational principles of the Action plan - person-centred, equity of access and sustainable workforce and systems - into the way the NDIS Support rules are implemented and operationalised:

- a. **Rights-Based Framework** - The rules must uphold the human rights of people with disability, consistent with the United Nations Convention on the Rights of Persons with Disabilities. This includes the right to dignity, privacy, independence, and protection from discrimination, especially in the context of complex, progressive, and often misunderstood conditions.
- b. **Person-Centred Approach** - Supports must be tailored to each participant's individual needs, goals, and circumstances. The rules should reflect the diversity of disability experiences, including those with complex, progressive, or rare conditions.
- c. **Equity of access** - The rules must ensure fair access to supports, regardless of location, disability type, or cultural background. People with disability should have equitable access to mainstream services and standard or generally available technology, especially when it is used to mitigate disability impacts.
- d. **Choice and Control** - Participants must retain autonomy over their support decisions, including how, when, and from whom they receive supports. The rules must not restrict access to supports that individuals deem necessary for their wellbeing and independence.
- e. **Sustainable workforce and systems** - Supports should be assessed using a whole-of-life value-for-money lens, recognising long-term benefits and cost-effectiveness. Investment in preventative and enabling supports should be prioritised to reduce future reliance on intensive services.
- f. **Evidence-Informed Practice** - Supports should be guided by both formal evidence and lived experience, including emerging and innovative practices. The system must

accommodate conditions with limited research, such as rare diseases, by recognising alternative forms of evidence and applying a least-restrictive, risk-based approach to ensure continued access to essential supports.

- g. Inclusion and Accessibility** - Supports should promote social and economic inclusion, enabling participation in community, education, employment, and recreation. Rules must be clear, consistent, accessible and easy to understand for all NDIS participants, providers, and planners.
- h. Flexibility** - The system must allow for flexible interpretation and application of support categories. Supports should not be limited to rigid lists but instead guided by principles that accommodate evolving needs and incorporate innovation and emerging technologies.
- i. Right to review** – All decisions regarding NDIS Supports rules, including the replacement supports, must be reviewable decisions. This ensures transparency, accountability, and the right of participants to challenge decisions that affect their access to essential supports.

1.2. Inconsistent Interpretation and Application

Through engagements with the DSS and NDIS, RVA understands that the current lists are intended to be broad and indicative, with room for interpretation. They are not intended to be exhaustive or all encompassing. However, RVA has routinely heard from the rare disease disability community and NDIS participants that the lists are being applied as definitive, rigid instruments by NDIS staff, Local Area Coordinators, plan managers, and support coordinators, often without appropriate consideration for individual circumstances and support needs.

The communication from the NDIA is confusing regarding who is responsible and accountable for helping participants understand how to spend their funding in line with the NDIS Supports rules, and what information should guide their decision making. This confusion and inconsistency has created anxiety among NDIS participants, who fear making mistakes that could result in debts, penalties or loss of funding.

RVA understands that the DSS intends to release an exposure draft of the updated rules for public comment. It is essential that this draft is accompanied by improved definitions, practical guidance materials, and interactive decision-making tools that empower participants to navigate the system confidently and independently. This will help to restore trust and ensure equitable access to supports.

Recommendations:

- 1. The draft operational documentation that supports the implementation of the NDIS Support rules must also be released for review and consultation.**

- 2. The NDIS must invest in comprehensive training for NDIS staff and providers that includes clear, consistent guidance for all stakeholders involved in interpreting and applying the rules.**

1.3. Clarify and Improve the Replacement Supports Framework

The current Replacement Supports process is overly complex, burdensome, and not fit for purpose. Supports that promote independence, dignity, and autonomy, such as smartwatches, smart assistive technology, and accessibility/communication applications, are subject to additional application requirements that create unnecessary delays and confusion. This process must be made more transparent, timely, and accessible for participants.

Communication aids

RVA has received consistent feedback from participants who rely on communication aids and applications for essential daily tasks. Many have experienced long delays, inconsistent decisions, and uncertainty. For people with severe communication challenges, including people with significant sensory impairments or cognitive or intellectual disabilities, delayed access to communication tools can infringe on their human rights, specifically, the right to use their preferred communication methods and receive information in formats suited to their needs.

RVA recommends that communication applications hosted exclusively on iOS devices, including iPads and tablets, be recognised as approved NDIS Supports. These tools are essential for functional communication and should be regarded as ‘disability-specific assistive technology’, not general household items. Currently, these items must either be explicitly included in a participant’s NDIS plan or approved through the Replacement Supports process, which adds unnecessary administrative burden and delays. Removing these supports from the Replacement Supports process would streamline access, reduce administrative overhead, and uphold the NDIS principles of choice, control, and inclusion.

Communication building tools

For participants who rely on communication boards and visual aids, printers and laminators are essential. These tools allow individuals and families to create and update communication materials flexibly and affordably. Compared to purchasing pre-made resources or relying on allied health professionals, this approach offers significant value for money.

Classifying these items as general household goods under the Replacement Supports process creates unnecessary barriers. Instead, they should be recognised as disability-specific assistive technology as they directly support communication needs and allow for timely adaptation to communication tools that are especially important for people with progressive or evolving conditions.

Replacement Supports eligibility criteria

RVA also believes the current eligibility criteria for replacement supports set an unreasonably high threshold for many people with disabilities caused by rare diseases. The requirement that an item must *“increase whole task independence and reduce or eliminate the need for a support worker or disability-specific assistive technology”* is unrealistic for many people with rare and complex disabilities.

In many cases, complete independence may not be achievable, but tools like smartwatches can still provide vital support, such as emergency alerts and medication reminders, which enhance autonomy and safety. Similarly, smart home devices, like voice-activated assistants, automated lighting, doors, blinds and calling systems, allow participants to control their environment, which is especially important for those with mobility or sensory impairments or those who use voice-commands or voice output communication devices.

Review process

RVA strongly advocates for the introduction of a formal review process for Replacement Supports. The current requirement to wait 12 months before reapplying after a denial of Replacement Supports severely limits access to essential supports and undermines participant rights.

Recommendations:

- 3. Amend the NDIS Supports Rules to recognise the following as approved supports, rather than subjecting them to the Replacement Supports process:**
 - Communication applications hosted exclusively on iOS devices, including iPads and other tablets.
 - Equipment used to create communication tools and resources, such as printers, laminators, and Braille label makers.
 - Smart home technologies that directly mitigate the functional impacts of disability (e.g. voice-activated assistants, automated lighting, and environmental controls).
- 4. Clearly define the Replacement Supports process, including:**
 - Transparent eligibility criteria.
 - Clear documentation requirements.
 - Timelines and responsibilities for decision-making by NDIS delegates.
- 5. Establish accessible and timely reviews and appeals mechanisms for all Replacement Supports decisions to ensure fairness and accountability.**
- 6. Enable streamlined re-approval for like-for-like replacement of previously approved supports when an item is damaged beyond repair, no longer functional, or requires an upgrade.**

1.4. Revisit Exclusions

The current NDIS Support Rules list several items as “not NDIS supports.” However, RVA has consistently heard from people living with rare disease disability that many of these supports can, and should, be considered on a case-by-case basis where they are directly related to a participant’s impairments and disability support needs. When supported by appropriate evidence from allied health professionals and assessed against the principles RVA has proposed, these supports may meet the criteria for inclusion as NDIS Supports.

Despite this, many participants’ families and providers are unaware that such flexibility exists. The lack of clarity around the “grey area” between excluded and potentially eligible supports creates confusion and may unintentionally prevent access to essential disability-related supports. In some cases, items appear on both the approved and excluded lists, further complicating decision-making and undermining confidence in the system.

RVA urges the NDIS to revise the Supports Rules to more clearly reflect the NDIS’ commitment to individualised, flexible support. The rules should explicitly acknowledge that certain supports may be considered NDIS-funded when justified by individual circumstances, professional evidence, and alignment with the participant’s goals and impairments.

RVA calls for the following supports to be reassessed as part of this consultation and recognised as eligible NDIS supports under Schedule 1 of the NDIS Supports Rules:

- Peer learning events such as disability-focussed rare disease conferences that provide significant opportunities for cost-effective training in how to manage disability impacts and achieve better outcomes.
- Disability-specific services for holiday care/Outside School Hours Care (OSHC) for young people with severe disability and/or intensive support needs who require specialist-trained support, and intensive support ratios, and may need to continue until 18 years of age. These are not mainstream costs but are directly related to the disability impacts and significantly exceed the needs of same-age peers.
- Specialist sensory assistive technology that is recommended by an appropriately qualified allied health practitioner.
- Adaptive play equipment (e.g. adaptive swings) especially in rural/regional/remote areas where there is no community or place-based alternative.
- Costs associated with recreational sports and activities, including uniforms and footwear where items must be adapted and customised to the individual’s disability support needs.
- Food and groceries when accessing Short Term Accommodation services delivered in a group setting.

- Pharmaceuticals, including food/fluid thickeners and nutritional supplements, that are disability-related and defined in Dysphagia and/or Mealtime Management Plan developed by an appropriately qualified allied health practitioner.
- Pharmaceuticals including complex bowel care products that are disability-related and required as part of a Complex Bowel Care Management Plan developed by an appropriately qualified allied health practitioner.
- Design and changes to specialist disability accommodation where an individual requires specific disability-related modification to toilets, grab rails, hoists or installation of smart assistive technology.
- Electricity generators and/or home batteries for power storage that is essential to ensure the safety and wellbeing of NDIS participants reliant on powered devices for daily functioning and essential wellbeing.
- Vehicle insurance for modified accessible vehicles, noting that car insurance is typically not considered a NDIS Support.

Recommendation:

7. **Revise the NDIS Supports Rules to clearly describe the process for case-by-case consideration of excluded supports.**

Conclusion

The NDIS is at a pivotal moment. The decisions made now about the NDIS Supports Rules will shape the future of disability support in Australia and directly contribute to the equity, dignity and human rights of people living with rare disease disability.

RVA calls on the government to work closely with people with lived experience, sector experts, and advocates to ensure the rules are fair, inclusive, and responsive to the needs of people living with rare disease disability and their families and caregivers.

Thank you for the opportunity to contribute to this consultation.

Contact:

Fiona Lawton

Disability Advocacy Manager

Rare Voices Australia

Email: fiona.lawton@rarevoices.org.au

References

1. Australian Government. Australian Public Service Commission. Definition of disability. September 2019. Accessed 12 June 2025. Available from:
<https://www.apsc.gov.au/working-aps/diversity-and-inclusion/disability/definition-disability>
2. Australian Bureau of Statistics. Disability, ageing and carers, Australia: Summary of findings. July 2024. Accessed 12 June 2025. Available from:
<https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>
3. Commonwealth of Australia, Department of Health. National Strategic Action Plan for Rare Diseases. Canberra; 2020. Accessed 12 July 2025. Available from:
<https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf>