



**National Disability Insurance Scheme (NDIS)
Improving Service Agreements**

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 means we work with all key stakeholders in the rare disease sector, including people living with a rare disease, governments, key peak bodies, researchers, clinicians, and industry. We collaborate with over 100 consumer-led rare disease groups/organisations ([RVA Partners](#)) across Australia 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) for rare disease community-led groups/organisations and invited sector stakeholders. Contributions from RDDN members and people living with rare disease disability 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. While individual rare diseases are uncommon, rare diseases collectively affect many Australians.

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."^{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 diseases 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 NDIS consultation on Improving Service Agreements conducted with the NDIS Quality and Safeguards Commission (NQSC).

On 12 March 2026, RVA participated in a NDIS-led peak body consultation on improving NDIS service agreements. The consultation explored the experiences of participants with NDIS service agreements, with a focus on understanding challenges, identifying what supports informed decision-making, and generating ideas for improving the overall system.

RVA understands that current service agreement practices often fail participants because they:

- are not consistently person-centred.
- create significant power imbalances between participants and providers.
- provide limited opportunities to negotiate terms or seek clarification before signing.
- may expose participants to unnecessary legal, financial or safety risk.

RVA advocates for system-wide reform that takes a modern, rights-affirming approach, strengthens participant autonomy, and protects participant privacy across the NDIS service ecosystem. Reforms must hard-wire stronger safeguards and accessible education so participants can exercise genuine choice and control without unnecessary risk or burden.

Detailed Consultation Feedback

RVA has compiled the following feedback from RDDN members and people living with rare disease disability.

Mixed messaging about whether service agreements are required

The National Disability Insurance Agency (NDIA) does not mandate the use of service agreements except for Specialist Disability Accommodation services. However, other parts of government, such as the Australian Taxation Office (ATO) require written agreements for GST exemption and to determine contractor/employee relationships.

This inconsistent messaging creates confusion for participants, nominees and providers about whether service agreements are required, what protections they offer and how consumer rights, dispute pathways, and legal safeguards apply.

There may be obligations under a range of legislative or regulatory frameworks, including:

- **Fair Work Act** – responsibilities that may arise when a participant is, or is treated as, the employer.

- **SCHADS Award** – minimum entitlements that may apply depending on the nature of the engagement.
- **Work Health and Safety (WHS)** – obligations relating to risk, safety and incident prevention within home or community settings.
- **Privacy Act 1988** – requirements for the handling, storage and disclosure of personal and sensitive information.

Without clear guidance, NDIS participants may unknowingly enter arrangements that expose them to unintended legal responsibilities or gaps in protection.

Clarity about the type of arrangement

NDIS participants and providers can engage in different service arrangements – employment agreements, contractor agreements, and provider agreements. Each arrangement triggers distinct risk, safety and cost implications for NDIS participants. These differences matter because they determine who is legally responsible for safety, pay, insurance and privacy.

Participants need a **plain English statement** at the beginning of any service agreement that clearly identifies:

- the type of arrangement.
- the likely relevant legal and regulatory requirements.
- who holds which obligations, risks and responsibilities.

“The agreements can be very dense and lengthy and for our cohort of people who are experiencing cognitive impairment... overly technical and difficult to understand.”

– RVA Partner organisation

Complex and legalistic format

Agreements are long, inconsistent and difficult to understand, and are rarely available in Easy Read, other languages, or other accessible formats. For people with rare disease disability—many of whom experience fatigue, fluctuating capacity, progressive decline or intellectual/cognitive disability—lengthy, legalistic documents create **unmanageable cognitive load**.

These barriers are even greater for priority populations, including Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse communities.

“Don’t make people wade through reams and reams of stuff... Very clear guidance... you just click on the box and it presents it for you.” – NDIS nominee, rare caregiver

The range of legal and financial obligations are spread across multiple government websites and formats, forcing participants and carers to stitch together essential information. The process is overwhelming and drives “tick-and-flick” behaviour—especially for people managing fatigue, pain, dysautonomia, cognitive impairment or progressive decline. This increases the risk that participants unknowingly accept terms that are unclear, unfavourable or inappropriate for **high-risk, high intensity care**.

“Put the key stuff up front... fees, cancellation, what goes wrong — that’s really the stuff that people care about.”

– RVA Partner organisation

Critical elements can be missed

Participants consistently report misunderstandings in areas that directly affect safety, continuity and cost, including:

- **Cancellation clauses** — when they apply, how fees are calculated, what is “reasonable,” and whether unplanned hospitalisations, acute episodes or disease flares are treated differently from routine cancellations.
- **Provider travel charges** — what can be charged, how travel time is calculated, when travel is billable
- **Hidden or poorly explained fees and conditions** — including shift loadings, PPE or clinical consumables for high-risk tasks, and nonstandard pricing.
- **Management of personal and privacy sensitive information** — what information is required, how it is stored, who can access it, how long it is retained, and how to avoid duplicating sensitive details across multiple providers.
- **Provider qualifications, registrations and background** — participants with rare disease disability want **visibility of provider competence**—insurance, worker screening, qualifications and specific training for **high-intensity supports** (e.g., ventilation support, seizure management, dysphagia management).

“You’re being told you’ve got to sign a service agreement, otherwise we’re not delivering services... you feel held over a barrel... it doesn’t ever feel like it’s a collaboration.”

– NDIS nominee, rare caregiver

Power imbalance and pressure to sign

Providers frequently require a signed agreement before services can commence or continue. Despite the significance of these documents, there is no consistent practice of

offering a pre-signature conversation, checking for understanding, or reviewing whether a participant's circumstances or goals have changed since the last agreement.

Participants may feel pressured to sign quickly to **avoid losing scarce, highly skilled workers**, or may sign without understanding.

A structured conversation ensures rights, responsibilities and risks are understood *before* signing.

Privacy and data security concerns

RVA has significant concern about the extensive personal information participants are required to provide as part of the service agreement process—NDIS numbers, addresses, dates of birth, contact details, family/guardianship information, and details of funded supports, **without clear explanations** regarding information storage, security, access or retention. Once shared, this information is difficult for participants to track or control

“Lots of bits of personal information... being distributed... we don't know what their data protection and management protocols are, [or] what server the information is held on.”

- RVA Partner

Service Agreement Reform

Improved education and accessibility

NDIS participants with rare disease disability navigate complex health and disability systems. Lengthy, legalistic documents cause overwhelm and confusion. These participants need options that **reduce cognitive load** and support varied decision-making styles—from highly engaged self-managers to those needing supported decision making or communication support. Options may include:

- **Easy Read**, large print, audio/video explainers and **Braille**, available **before and after** signing.
- **One page summaries** with the essentials up front (fees, cancellations, travel, privacy, complaints).
- **On-demand explanations** (expandable “what this means” for tricky topics like cancellation fees or travel charging).

- **Case study videos** showing real scenarios (solo, or with a coordinator/family member), modelling negotiation, continuity of care considerations and risk management.

“A digital checklist that says: before I sign... we’ve discussed provider travel, cancellation fees... I’m comfortable with how the organisation will manage my data, privacy, complaints.” – NDIS nominee, rare caregiver

Innovative digital reform

RVA proposes a single, integrated digital service agreement process that replaces fragmented, provider-led contracts with guided, participant-led system in the NDIS portal.

This system would guide participants and providers through the agreement process in a clear, accessible and consistent way.

A mandatory pre-signature conversation would be a foundation of this model.

The digital system would:

- Provide information in easy-to-understand formats and be tailored to participants’ communication and cognitive needs.
- Require both participants and providers to contribute directly to the online agreement, enabling participants to clearly express their values, preferences and priorities.
- Embed safeguards through a transparent digital workflow with guided checklists, clear prompts and fewer provider written legal documents.
- Provide participants with a simple checklist to confirm their understanding of key issues like travel, cancellations, privacy and complaint options.
- Support different decision making needs by including optional videos, fact sheets, guided explanations and step-by-step prompts.
- Strengthen privacy and data protection through Australian Government security standards.
- Improve transparency and allow the NDIA to better understand participant–provider relationships and market gaps.
- Reduce administrative burden through **pre-fillable, customisable templates**.
- Reduce hidden or paper-based agreements that remove safeguards or contain restrictive clauses (such as noncompete terms that interrupt continuity of care).

“Participants could nominate providers through the NDIS portal and all legal protections would be in one place... you could select the right pre-formatted template agreement for different services... have defined elements for negotiation with providers...”

“The NDIS and NQSC would have increased visibility and opportunities for safeguarding. You could type in ABNs and see who is working with who, identify participants at risk who have no service agreements in place with providers, and follow them up, identify providers working in thin markets and link them up with participants...”

– RVA Disability Advocacy Manager

Improved Data Management

RVA urges the NDIS and NQSC to introduce **clear national guidance, enforceable minimum data standards and strengthened oversight mechanisms**. This would include a standard that limits collection to essential information, requires transparent explanations of storage, security, retention and access arrangements, and guarantees participants access to their signed agreements.

Recommendations

1. Provide clear guidance on when and why service agreements are required

The NDIA and NQSC should develop clear guidance on when service agreements are required, including how service agreements interact with requirements under other systems such as the ATO and GST.

2. Clear Identification of the type of arrangement

All service agreements must clearly state in plain English the type of arrangement being entered into, the key laws likely to apply and who holds which obligations, risks and responsibilities.

3. Participant-led process

Service agreements processes must be participant-led, and include safeguards to address power imbalances and prevent coercion.

4. Mandatory pre-signature conversation

The NDIA and NQSC should mandate a documented pre-signature conversation between participant and provider before any agreement is signed. This conversation should confirm the participant’s goals and expectations, all negotiable terms (including fees, cancellations, travel charges and pricing), how personal information will be used and stored, and the available complaint and dispute pathways.

Participants should have the option to opt out for stable, recurring arrangements where no changes are required.

5. Improved accessibility and education

The NDIA and NQSC should develop service agreement templates with essential terms and optional additional sections for complex supports in a range of accessible formats including Easy Read versions, simple checklists, audio/video explanations, and plain-English guidance scaled to the complexity of the supports being delivered.

6. Strengthen data and privacy standards

The NDIA and NQSC should develop clearer guidance and minimum data standards so that participant privacy and data security are treated as core safeguards within the service agreement process.

7. Integrated digital solution

RVA recommends the development of a single, integrated digital service agreement system within the NDIS portal, modelled on familiar myGov services.

8. Co-design and usability testing

All service agreement templates, digital systems and educational materials must be codesigned and usability-tested with people living with rare disease disability, including those with intellectual or cognitive disability, as well as carers and nominees.

Conclusion

RVA calls on the NDIA and NQSC to act now to reform NDIS service agreement processes, so they are participant-led, accessible, and safe. RVA welcomes the opportunity to work collaboratively with the NDIA and NQSC to explore and progress innovative reform solutions provided in this submission, to better meet the needs of people living with rare disease disability.

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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

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