



**National Disability Insurance Scheme (NDIS)
2025-2026 Annual Pricing Review**

February 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 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."^{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 the needs of 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 Annual Pricing Review (2025-2026).

RVA's submission is informed by our previous contributions to consultations on NDIS Pricing and Pricing Arrangements, and we share these earlier submissions for consideration:

- RVA Submission (February 2025) – [Registration of NDIS Participants Who Self-Direct Their Supports – NDIS Quality and Safeguards Commission](#)
- RVA Submission (November 2024) – [NDIS Pricing and Funding Arrangements – Independent Health and Aged Care Pricing Authority](#)
- RVA Submission (March 2024) – [NDIS Participant Experience in Rural Regional Remote Australia](#)

Our prior submissions outline persistent barriers—clinical complexity, diagnostic uncertainty, fluctuating needs, thin markets, limited informal supports—and propose pricing reforms aligned to the **Action Plan**.

Rare disease disability presents multisystem, high-risk and fluctuating support needs that current NDIS pricing arrangements do not recognise. Without structural reform, participants with rare disease disability will continue to experience inequitable outcomes, thin markets, and workforce withdrawal.

RVA advocates for NDIS pricing and market settings that deliver the following for participants with rare disease disability:

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

Improved outcomes

Implementing the innovative solutions presented in this submission will deliver the following outcomes for the NDIS, participants and provider:

- Reduced participant out-of-pocket spend on training and provider travel.
- Increased provider willingness to deliver supports in thin markets
- Reduction in service disruption for participants with complex rare disease disability.
- Increased uptake of qualified providers for high-risk supports.
- Improved plan utilisation rates for participants requiring high intensity supports.

Responses to the participant specific consultation questions are provided in **Appendix 2**.

NDIS Pricing Arrangements and Rare Disease Disability

RVA supports NDIS pricing reform that better reflects complexity, geography, workforce capability and sustainability, and participant outcomes. However, **differentiated pricing based primarily on provider registration status, without corresponding plan-level safeguards, risks entrenching inequity**, particularly for participants with rare disease disability who already experience thin markets and workforce shortages.

Participants with rare disease disability disproportionately rely on self-directed and ‘Services-for-One’ models, and bespoke participant-led workforce training with unregistered providers because these approaches enable targeted, value for money quality support for their rare disease disability needs that mainstream organisations frequently cannot, or do not, provide.

Current pricing and compliance settings create a perverse incentive where providers prioritise training required by the NDIS Quality and Safeguards Commission (NQSC) and activities that support audits and registration, rather than investing in intensive, participant-specific training needed for disability-related health supports, complex behaviour and communication.

In practice, **this shifts risk and training responsibility onto participants and families** rather than pricing it transparently and systemically into the NDIS. Any changes to pricing arrangements must ensure continued access to these participant-led models without adding complex administrative burdens to participants.

RVA’s Position on Differentiated Pricing

RVA acknowledges that registered providers incur additional compliance and governance costs. However, RVA’s lived experience evidence demonstrates that registration status does not reliably correlate with capability to deliver complex, rare disease disability specific supports.

Differentiated pricing that rewards registration without recognising complexity, training intensity, safeguarding and participant outcomes risks disadvantaging the very cohorts the NDIS is designed to support.

Participant-specific training must be transparently funded. RVA proposes a standalone needs-based proportionate funding allocation for NDIS participants that can incentivise service providers to train their workforce to meet the specific needs of their NDIS clients.

Differentiated pricing must consider geography. In thin markets, participants may have no genuine choice between registered and unregistered providers.

NDIS Provider Travel and Reporting Fund

RVA urges the National Disability Insurance Agency (NDIA) to establish a centrally administered Provider Travel and Reporting Fund that allows providers to invoice the NDIA directly for legitimate scheme-driven activities, including:

- Provider travel
- NDIS required report writing
- Multi-stakeholder engagement
- Additional NDIA requested evidence.

Under current arrangements, these costs are drawn from participants' NDIS plans, often without adequate or any specific funding allocation for them. As a result, participants are effectively **underwriting system and compliance functions from their individual therapy and support budgets**, frequently at the expense of essential supports.

A centrally administered approach would promote **equitable access regardless of postcode** and significantly improve provider willingness to service thin markets. Providers could claim actual, auditable costs directly from the NDIA, preserving participants' funded support hours while strengthening accountability.

This reform would also improve NDIA visibility of provider activity by location, creating opportunities for more responsive commissioning, integrated service models, and market stewardship, particularly in rural, regional and remote areas.

"It would be extremely helpful... to make allowances for suitable workers to travel without soaking up too much of the participant's budget." - NDIS nominee (rare caregiver)

Workforce Capability Incentives

NDIS pricing does not adequately fund the additional time and costs required for clinical liaison, documentation, supervision, on-the-job training, or the higher insurance and compliance obligations borne by registered providers. This underfunding contributes to workforce shortages, high turnover, and provider reluctance to accept participants with more complex support needs.

RVA supports **targeted workforce capability incentives**, including a professional advancement loading, a supervision and mentoring allowance, and a substantial increase in funded shadow shifts for high-risk participants (well beyond current six-hour norms).

These measures would strengthen workforce capability, reduce turnover, improve continuity of care, and incentivise providers to deliver supports to NDIS participants with higher and more complex needs.

Participant Training Allocation

People living with rare disease disability frequently require support workers who are trained in high-risk, condition specific and communication specific practices. These needs span disability related health supports, manual handling, mealtime management, seizure management and complex communication strategies.

Despite this, under current NDIS pricing settings, **participants are personally underwriting the cost of training**, drawing from their individual plans to ensure support workers can deliver safe, competent care. When plans are not adequately or transparently allocated for training, participants may be forced to **forego essential workforce training** just to preserve enough hours of direct support.

RVA proposes a dedicated **Participant Training Allocation** that is:

- **Risk-based and proportionate** to participant complexity.
- **Transparent** in how the allocation is calculated and applied.
- **A stated support**, ensuring training costs no longer erode the participant's core support hours.
- **Outcome driven**, enabling providers to acquire the competency needed to deliver safe, high-quality supports to participants with rare disease disability.

This training allocation would strengthen workforce capability for rare, complex and high-risk participants. It would improve continuity and safety of care and increase provider willingness to support complex cohorts, particularly in thin markets.

“Participants are carrying the financial risk of travel costs, undermining their ability to access equitable outcomes. This burden must shift to systemic funding models.” - RVA Partner (rare disease group/organisation)

Tier 2 High Intensity Loading for Compounded Complexity

Many people living with rare, complex, and progressive conditions experience multiple high-intensity support needs simultaneously. For example, this could include a combination of daily disability-related health supports such as dysphagia, respiratory management, diabetes care, continence, or wound/pressure care alongside intensive and complex behaviours requiring proactive strategies, restrictive practices, or specialist behavioural intervention.

Under the current NDIS Pricing Arrangements, participants are eligible for a high-intensity support rate if they meet one of these criteria (high-intensity personal activities, intensive/complex behaviour support, or disability-related health supports). However, the pricing framework does not recognise the **compounded risk, workforce skill requirements, or provider costs where multiple high-intensity domains coexist**, which is particularly common in rare disease disability.

To ensure safe, sustainable support delivery and genuine value for money, RVA recommends the introduction of an additional “**Tier 2 High Intensity**” loading. This tier would apply when a participant requires two or more high intensity support types concurrently, reflecting the significantly elevated staffing competence, coordination effort, clinical oversight, and continuity-of-care needs.

Creating this additional tier would better align the pricing model with the real demands of supporting people with rare disease disability and prevent service gaps that currently arise when providers are unable to meet complex needs under a single-intensity price limit.

“Price signals must match clinical reality: rare, degenerative neurological conditions involve rapid change, multisystem risk and intensive coordination—flat price caps can’t buy safe care.” - RVA Partner (rare disease group/organisation)

Recommendations

1. **Differentiated pricing:** RVA supports price uplifts for registered providers that reward demonstrable quality and safeguarding, while protecting participant choice and control, especially for participants with self-directed supports.
2. **NDIS Provider Travel and Reporting Fund:** Establish a centrally administered mechanism to fund actual provider travel, reporting and compliance costs, and remove this responsibility from participant budgets.
3. **Workforce capability incentives:** Introduce a professional advancement loading, supervision/mentoring allowance and significantly expand ‘shadow shift’ funding for high-risk cohorts.
4. **Participant training allocation:** Introduce a dedicated, risk-based Participant Training Allocation that fully funds condition-specific workforce training so that rare, complex and high-risk participants are no longer forced to sacrifice essential support hours to ensure safe, competent care.
5. **Tier 2 high intensity support rate:** Establish a Tier 2 High Intensity rate to reflect the real workforce skill and coordination demands when participants require two or more high intensity supports concurrently.

6. **Independent pricing stewardship by IHACPA:** transition pricing arrangements to IHACPA for transparent, evidence-based stewardship.
7. **Protect choice and control:** Ensure pricing reform enhances access for people living with rare disease disability, particularly in thin markets and protects the rights of participants to self-direct or self-manage their supports.

Conclusion

RVA urges the NDIA to act on the reforms outlined in this submission to strengthen equity, safety, and access for people living with rare disease disability and to ensure pricing arrangements genuinely reflect the complexity of their support needs. These reforms will also contribute to restoring safety, equity and sustainability across the entire NDIS

RVA welcomes the opportunity to collaborate closely with the NDIA on this work and invites a meeting to discuss how these innovative solutions can be progressed and implemented in partnership with the rare disease sector.

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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.

Appendix 2 – RVA Responses to Participant Consultation Questions

Q1. Why do you choose a registered or unregistered provider?

RVA members report that choice is often driven by **availability rather than preference**, particularly outside metropolitan areas. Participants with rare disease disability may prefer registered providers for complex supports due to training, incident management, supervision and compliance systems, but in many locations only unregistered providers are available, or registered providers will not travel due to uncompensated costs.

For routine supports, participants may choose unregistered providers to maximise hours within constrained budgets. For complex or high-risk supports, registered providers are often clinically and practically necessary.

Q2. When choosing a provider, what matters most?

What matters most to participants with rare disease disability is:

- Capability to meet complex needs, including rare disease knowledge
- Reliability and continuity of workforce
- Geographic reach and willingness to travel or provide in home services-home services
- Ability to coordinate with health teams with good health literacy skills
- Safety, quality systems and supervision, particularly for high intensity supports
- Continuity and cultural fit (critical for communication/behavioural needs).

Cost is important, but participants consistently report that reduced hours resulting from travel costs or insufficient pricing compromises outcomes and safety.

Q3. If registered providers could charge more than unregistered providers, how would this affect your choice?

For many participants with complex rare disease disability, it would not represent a genuine choice. If higher prices result in fewer funded hours, participants may be forced to downgrade provider quality, reduce support, or go without essential services.

Differentiated pricing risks entrenching inequity unless accompanied by plan funding adjustments and transparent safeguards ensuring participants are not financially penalised for needing higher quality supports.

Q4. If registered providers charged more than unregistered providers, would you switch to unregistered to get more hours even if quality/safeguards were lower?

Some participants may feel compelled to do so, not because they prefer lower safeguards, but because funding constraints leave no alternative. This is particularly concerning for

participants requiring intensive, behaviour, communication or disability related health supports, where quality and supervision are critical to safety and outcomes.

Q5. If you need specialised, complex support, have you had trouble finding providers?

RVA hears from our RVA partner organisations and people living with rare disease disability about persistent shortages of allied health, behaviour support and skilled disability support workers with rare disease capability, particularly in regional, rural and remote locations. Thin markets, travel disincentives and inadequate pricing structures further restrict provider availability, even when plans are appropriately funded. A **Participant Training Allocation** and a **NDIS Provider Travel and Reporting Fund** would help address these barriers by improving provider willingness and capacity.

“People in isolated or rural areas do not always have access to the required supports even before worrying about how good the support is.” - RVA Partner (rare disease group/organisation)

Q6. How important are provider quality systems (incident management, trained workers, supervision)?

Quality systems are essential for participants with complex, progressive, or high-risk support needs. These systems have real costs that must be built accurately into pricing.

Increased funded buddy/shadow shifts, well beyond the current six-hour annual allocation, are essential for safe service delivery for people living with rare disease disability. Six hours is not fit-for-purpose, as it does not reflect the complexity, risk profile or specialised skills required to support rare, multisystem and often high-risk conditions.

Many rare diseases involve disability-related health supports such as seizure management, dysphagia, respiratory care, autonomic instability, complex behaviour linked to pain or fatigue, condition-specific manual handling, and non-standard communication. These competencies cannot be learned safely in a single short induction. Competence for high-risk supports requires multiple supervised sessions across the year, for example, safe positioning for aspiration prevention, mealtime management, seizure monitoring, respiratory equipment use, safe transfers where joint laxity increases injury risk, and early recognition of sensory or behavioural escalation.

With high workforce turnover and frequent introduction of new staff, the six-hour cap is quickly exhausted, leaving no funded time for reinforcement, supervision, modelling of safe practices, behaviour support coaching or updates aligned to changes in the person’s condition.

Insufficient training results in chronic under-preparedness and heightens risks such as aspiration pneumonia, hospitalisation, fractures, behavioural escalation, communication

breakdown, loss of function, and trauma for both workers and participants. Preventing these harms requires structured, ongoing, adequately funded training built into pricing arrangements. Without this, participants are left to personally underwrite workforce capability, compromising safety, outcomes and equity.

Workforce capability incentives and a **Participant Training Allocation** would strengthen the market for participants with rare disease disability.

Q7. If a provider with stronger quality systems charged more, would you still choose them?

Participants would choose higher quality providers if plan budgets were adequate to sustain the required level of support. Without corresponding funding adjustments, higher prices simply reduce service volume and worsen inequity.

Q8. For therapy supports, what matters most when choosing a therapist?

RVA understands that individuals will select therapy supports for a range of reasons, and that NDIS participants with rare disease disability actively seek therapists who can offer:

- Person-centred approach
- Specific expertise in rare disease disability and multi-system presentations.
- The ability to coordinate across disciplines and with healthcare services.
- Travel willingness for in-home/community contexts.
- Ability to prepare good evidence to support funding requests.

Q9. If providers who meet higher quality standards could charge more, what information would you need?

RVA has previously recommended improved data transparency and provider performance information to support informed choice.

Participants would need:

- Clear, accessible guidance on what “quality standards” entail.
- Transparent provider performance information (complaints, incidents, outcomes) in plain English.
- Clear, accessible information on provider capability and quality.
- Decision support tools and guidance for comparing value for money.
- Assurance that plan funding reflects complexity, not averages.
- Confidence that higher prices will not reduce access to essential supports.

Q10. What concerns you most about differentiated pricing based on quality/complexity?

The primary concerns that RVA hears from NDIS participants living with rare disease disability are:

- Reduced hours of support for people with complex needs.
- Increased inequity between metropolitan and regional participants.
- Risk shifting from systems to individuals—shifting from systems to individuals.
- Participants being forced to trade safety for affordability.
- Automated budget calculation and alignment to tiers.

Without structural protections, differentiated pricing may worsen outcomes for those already experiencing the greatest disadvantage.

“We need equity of outcomes, not just equity of access. Thin markets and travel burdens significantly reduce the benefits of funded supports for regional participants.” - NDIS participant with rare disease disability

Q11. If NDIA introduced different prices for SCCP, how would this affect your choice?

RVA maintains the position that differentiated pricing, must be tied to **demonstrable capability** for complex cohorts.

Q12. Since the 1 July 2025 therapy travel change, is it hard to find a therapist who will travel?

Yes, for many participants, access has worsened. RVA recommends a **Provider Travel Fund** and appropriate geographic loadings to restore in-home access and equity.

Q13. If you had your choice, what would you prefer (re: therapy travel)?

A system where **participant therapy hours are protected** and **travel is funded centrally** (with accountability), plus calibrated regional/remote loadings and allowance for necessary overnight stays.

Q14. Why do your therapists travel to you?

For complex rare disease, effective therapy is often in situ (home/environmental context), essential for safe transfers, positioning, dysphagia management, and equipment setup—especially where clinic access is distant or impractical. Pricing arrangements must recognise this.

Q15. If pricing changes were made, what would help you adjust?

To improve transparency around changes to pricing arrangements and to enable effective implementation NDIS need published rationale and methods (IHACPA style transparency), adequate transition periods and grace windows, and clear participant and provider guides, worked examples, and accessible formats.

References

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