



**National Disability Insurance Scheme (NDIS)
Evidence Advisory Committee
Positive Behaviour Support
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 advocates for the best outcomes for Australians living with a rare disease, and their families and carers.

RVA's disability advocacy is non-disease specific and focuses on shared disability experiences and systemic impacts across the rare disease population, including within the National Disability Insurance Scheme (NDIS).

RVA is proudly delivering the [Rare Disease Disability Project](#) (the Project) for the 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 ([RVA Partners](#)) 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 Disease Disability

Rare diseases are often serious and progressive, exhibiting a high degree of symptom complexity, with significant disability impacts on communication, cognition, behaviour, physical functioning, mental health, and social, community and economic participation across the lifespan.

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.**

RVA has identified five (5) broad categories of rare disease disability:

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.

Previous Submission – September 2025

RVA previously provided a detailed submission ([RVA Submission](#)) to the NDIS Evidence Advisory Committee (EAC) as part of the September 2025 consultation on NDIS supports, which outlined the systemic challenges faced by people living with rare disease disability in evidencing and accessing appropriate NDIS supports.

RVA called for:

- explicit recognition of rare disease disability as a distinct population cohort
- the application of an evidence-informed (not evidence exclusive) assessment approach
- acknowledgement of safeguarding risk and restrictive practice exposure as indicators of support necessity
- and consideration of progressive and fluctuating disability trajectories when assessing supports.

RVA also emphasised the systemic consequences of under support, including cost shifting, service breakdown and avoidable harm.

RVA recommended that the EAC's advice to government ensures that people living with rare disease disability are not disadvantaged by assessment frameworks that do not adequately reflect rarity, complexity, progression, or safeguarding risk.

The recommendations called for remain current and unresolved and inform RVA's engagement with the EAC. This includes in the assessment of Positive Behaviour Support as this is frequently an essential support for children, young people and adults living with rare disease disability.

Rare Voices Australia's Submission

RVA welcomes the opportunity to make a submission to the NDIS EAC's third consultation on supports under review. This submission addressed **Positive Behaviour Support for older children and adults**.

RVA and RDDN members believe that Positive Behaviour Support, as defined and regulated under the NDIS Quality and Safeguards Commission framework, is appropriate, necessary, and in many cases essential, for people living with rare disease disability.

Rare Disease Disability and Behaviour

People living with rare disease disability experience behaviours of concern in ways that differ in both **cause and trajectory** from much of the broader disability population. Across the rare disease population, disability frequently involves medical comorbidity (including pain, fatigue, seizures or autonomic instability), severe or profound intellectual disability, complex or absent verbal communication and sensory processing differences. In some cases, there may also be co-occurring autism, anxiety or neuropsychiatric features. There is a high reliance on consistent environments and trusted caregivers.

Across rare disease disability, behaviours of concern commonly arise from **neurodevelopmental differences, progressive loss of function, or episodic deterioration** associated with worsening health, fatigue, pain, autonomic instability, seizures or anxiety. Many individuals experience **progressive loss of communication capability**, meaning that behaviour increasingly becomes a primary form of expression of unmet need, distress or physiological change

Rare disease disability is also characterised by **high medical complexity and system fragmentation**, with individuals frequently moving between home, education, shared living, community and health service settings. Transitions, workforce turnover, unfamiliar environments and inconsistent supports are common.

Importantly, behaviours of concern in rare disease disability often emerge during periods of **unrecognised clinical or functional decline**. When changes in behaviour are not understood within the context of progression or episodic deterioration, there is a heightened risk that behaviour will be misinterpreted and managed **through reactive, restrictive or exclusionary practices**, including over-reliance on medication, service withdrawal due to perceived "complexity", or the use of restrictive practices.

People living with rare disease disability are therefore at **increased safeguarding** risk, particularly those with severe or profound intellectual disability, complex communication needs, and high or unpredictable behavioural presentations. These risks are compounded in

thin markets and workforce-constrained services, where access to specialist expertise may be limited and continuity of care difficult to maintain.

On this basis, RVA considers that people living with rare disease disability constitute a distinct disability group for whom Positive Behaviour Support is frequently essential.

Why Behaviour Changes Over Time in Rare Disease Disability

Behaviour in rare disease disability often changes as neurological function, communication capacity, physical ability and health stability shift over time. Progressive, degenerative and fluctuating conditions mean that behavioural presentation may worsen, change in form, or intensify as capacity declines or fluctuates.

The nature of rare disease disability therefore requires an approach that can **adapt over time**, respond to deterioration or fluctuation, integrate multiple supports, and provide a structured alternative to crisis-driven responses. Positive Behaviour Support functions as an **adaptive, preventative and safeguarding framework** capable of responding to changing needs across the life course.

Positive Behaviour Support enables supports to evolve alongside these changes by maintaining a shared, function-based understanding of behaviour that can be continuously reviewed and adjusted.

The Value of Positive Behaviour Support for Rare Disease Disability

Positive Behaviour Support delivers clear and material benefit for people living with rare disease disability where behaviours of concern arise from **complex neurological, cognitive, sensory, communication and medical factors**.

It provides a structured, individualised framework to identify behavioural drivers — such as **pain, anxiety, environmental mismatch, cognitive decline or communication breakdown** — and to implement proactive strategies that enable people to participate safely in daily life. Its value lies in its capacity to respond to complexity and change over time, rather than relying on static or one-off interventions.

From a **safeguarding perspective**, Positive Behaviour Support is critical. RVA understands from the NDIS Commission that **restrictive practices cluster in cohorts** with severe disability, complex communication needs and high support requirements — characteristics common across rare neurodevelopmental and progressive conditions. Progressive and fluctuating conditions, combined with high rates of communication disability and medical complexity, significantly increase vulnerability to restrictive practices when behaviours escalate. Positive Behaviour Support provides a structured alternative to by enabling early indicators of distress, preventative strategies, and reduced reliance on restrictive, pharmacological or exclusionary practices.

Quality Positive Behaviour Support, as regulated under the NDIS Quality and Safeguards Commission framework, prioritises **human rights, dignity, skilled assessment and ongoing review**. For people living with rare disease disability, its value cannot be measured solely through reductions in challenging behaviour or improvements in functional capacity. Positive Behaviour Support is often most effective when it maintains safety, dignity and participation as capacity plateaus or declines. In this context, **maintaining stability, preventing escalation and avoiding restrictive practices** are legitimate and important outcomes.

Positive Behaviour Support also plays a **central coordinating role**, enabling multiple supports including therapies, environmental adjustments, communication supports, assistive technology and person-to-person supports, to operate coherently across different settings. This coordination supports workforce confidence and service continuity, reducing the risk of service withdrawal, exclusion from shared living, education, employment or community settings, and avoidable crisis.

When assessed longitudinally, Positive Behaviour Support represents **value for money** for the NDIS for people living with rare disease disability. RVA partners consistently report that under-investment in Positive Behaviour Support results in preventable cost shifting, including avoidable hospital presentations, service breakdown and increased reliance on crisis responses. By contrast, well-funded Positive Behaviour Support supports continuity of care, safeguards participation and reduces downstream costs across both the disability and health systems.

Positive Behaviour Support delivers benefit across all five (5) RVA rare disease disability categories:

1. **Neurological and neurodevelopmental conditions**, where behaviour is shaped by lifelong differences in communication, sensory processing and regulation
2. **Progressive and degenerative conditions**, where supports must adapt as skills are lost and behavioural expression changes
3. **Episodic and fluctuating conditions**, requiring flexible responses to variable health and functional capacity impacts
4. **Children with delayed development**, where early, preventative and non-restrictive responses reduce longer-term risk
5. **Undiagnosed rare conditions**, where function-based support is required in the absence of diagnostic certainty.

Limits of Comparing Positive Behaviour Support to Other Supports

For many people living with rare disease disability, Positive Behaviour Support is the **only structured support capable of maintaining safety and participation** across multiple settings over time. It functions as a core, rights-based safeguarding framework that coordinates and integrates other supports.

RVA therefore considers that Positive Behaviour Support **should not be assessed as a single intervention** to be compared against individual supports such as therapies, communication supports or environmental adjustments. Doing so risks under-estimating its value, mischaracterising its role, and disadvantaging people with rare disease disability whose needs do not conform to static or short-term evidence models.

Instead, therapies, environmental adjustments, communication supports or assistive technology are **most effective when delivered within a Positive Behaviour Support framework** that adapts as needs change.

Outcomes and Evidence for Rare Disease Disability

For people living with rare disease disability, the value of Positive Behaviour Support cannot be captured through short-term or static outcome measures. Rare disease trajectories are frequently **progressive, degenerative or fluctuating**, meaning that behavioural presentation may worsen over time as cognitive, communication or physical capacity changes. In this context, Positive Behaviour Support is often most effective not because it produces sustained behavioural improvement, but because it **maintains safety, dignity and participation as capacity plateaus or declines**.

Outcomes for this cohort cannot be limited to reductions in challenging behaviour or short-term functional gains. Meaningful outcomes instead include **early identification of functional deterioration, timely adaptation of supports, sustained participation, reduced exposure to restrictive practices, and the preservation of safety and dignity over time**. Outcome frameworks that assume stability, improvement or discrete intervention effects risk underestimating the value of Positive Behaviour Support for people whose needs evolve.

For rare disease disability, peer-reviewed research evidence on Positive Behaviour Support is inherently limited by **rarity, clinical heterogeneity and small population sizes**. As a result, **lived experience evidence** from people with rare disease disability, families, carers and specialist practitioners is essential to understanding how behaviours of concern present, change over time and respond to support in real-world settings. An evidence-informed approach must therefore value lived experience alongside published research when assessing the appropriateness and effectiveness of Positive Behaviour Support for rare disease cohorts.

Recommendations

1. **Recognise rare disease disability as a distinct disability group**, including for the purposes of EAC assessment of Positive Behaviour Support.
2. **Explicitly consider the relevance of** Positive Behaviour Support across all five (5) rare disease disability categories identified by RVA.
3. **Acknowledge** Positive Behaviour Support as a **rights-based safeguarding framework** for rare disease disability, and not a discrete or interchangeable intervention
4. **Ensure** Positive Behaviour Support **remains available for people with progressive, fluctuating and highly complex disability.**
5. **Apply an evidence-informed, not evidence-exclusive**, approach to Positive Behaviour Support for rare disease disability cohorts, recognising that success is often measured in adaptation, safety and dignity over time—not improvement alone.

Conclusion

RVA encourages the EAC to ensure that its advice to government reflects the distinct experiences, trajectories and safeguarding needs of people living with rare disease disability. Doing so will support more accurate assessment of Positive Behaviour Support, better alignment with the NDIS Quality and Safeguards Framework, and more equitable outcomes for people with complex, lifelong and changing support needs.

Contact:

Fiona Lawton

Disability Advocacy Manager

Rare Voices Australia

Email: fiona.lawton@rarevoices.org.au

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]