Independent Health and Aged Care Pricing Authority

NDIS Pricing and Funding Arrangements

Rare Voices Australia Submission
November 2024

About Rare Voices Australia

Rare Voices Australia (RVA) is the national peak body for the estimated two million Australians living with a rare disease.

RVA provides a strong, unified voice to advocate for policy as well as disability, health, and other systems that work for people living with a rare disease. RVA's work is non-disease-specific and is based on the commonalities of the approximately 7,000 different rare diseases.

Our person-centred focus sees us working with all key stakeholders, including people living with a rare disease, over 100 RVA Partners (rare disease groups/organisations), 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 welcomes the opportunity to provide a Submission to the Independent Health and Aged Care Pricing Authority (IHACPA) on the *Review of NDIS Pricing and Funding Arrangements.*

We estimate that there are approximately 100,000 participants currently receiving NIDS funded supports.

What Is a Rare Disease?

A disease is rare if it affects fewer than five in every 10,000 people. There are approximately 7,000 different 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 in itself 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.

Rare diseases are often serious and progressive, exhibiting a high degree of symptom complexity, leading to significant disability, health, and psycho-social challenges.

Most people with a rare disease meet the Australian government's definition of having a disability, being a "limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities". This includes the estimated 100,000 NDIS participants with severe to profound rare disease disability impacts.

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.

RVA's Submission

Rare Voices Australia (RVA) is pleased to contribute to IHACPA's consultation on the National Disability Insurance Scheme (NDIS) pricing and funding arrangements.

Representing over two million Australians living with rare diseases, including approximately 100,000 NDIS participants, we provide a unified voice advocating for sustainable, equitable, and effective pricing frameworks tailored to the needs of this cohort.

NDIS participants with rare disease disabilities experience inequities in accessing services and achieving outcomes due to the complex nature of their conditions, geographical disparities, and thin markets. The current pricing structure inadequately reflects the costs of specialised support required for this group.

RVA supports the recommendations from the 2023 Independent Review of the NDIS report, Working together to deliver the NDIS, for an independent body to oversee pricing, consideration of alternative commissioning models and outcome measures, and the need for drivers for market innovations. We invite the IHACPA to explore these opportunities as part of a new NDIS pricing framework.

We recognise that the NDIS Pricing review is complex, and occurs during significant disability sector reform, workforce shortages, and pressures on providers to absorb increasing operational costs associated with wage increases, compliance, quality assurance, mandatory registration, and workforce skill development.

We are pleased that the Australian Government is seeking evidence-based, data-driven pricing advice from IHACPA as part of the disability reform agenda. However, RVA is aware that the NDIS, and the state and federal governments in general, currently do not have a rare disease data management strategy to inform quality policy and pricing reform. RVA welcomes the opportunity to co-design in the development of pricing models to ensure they reflect the lived experiences of NDIS participants with rare disease disabilities.

In preparing this Submission, RVA engaged with our RVA Partners (rare disease groups/organisations), individuals, and families/carers living with rare disease disability impacts. Their observations, concerns, and recommendations are reflected in this Submission and quotes are included.

> *"In a harmonised pricing, alternative commissioning model there should be the opportunity to combine workforce from NDIS, aged and veterans care, enable the portability of skills, entitlements, and qualifications, create resilience in the workforce and sustain quality supports over time."*

Principles to guide a new NDIS pricing framework

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 supports changes to the NDIS pricing that align with the principles of the Action Plan:

- **Person-centred**
- **Equity of access**
- **Sustainable systems and workforce.**

RVA's submission includes recommendations that also align with IHACPA's principles outlined in *A Fresh Approach to NDIS Pricing* of harmonising aged care and disability pricing, supporting workforce sustainability, and promoting equitable outcomes:

- **Equity:** RVA's recommendations address the disparities in access and outcomes for rare disease participants.
- **Sustainability:** Workforce-focused pricing reforms ensure long-term sector viability.
- **Data-Driven Insights:** RVA urges IHACPA to integrate rare disease-specific data into pricing analyses to create tailored and evidence-based recommendations

An effective and sustainable NDIS pricing strategy must account for the needs of NDIS participants, disability support workers, providers, and the government.

Harmonisation of some elements across the care and support sector to include NDIS alongside aged care and veterans' care could provide opportunities for a sector-wide workforce strategy and cost-effective delivery of services. However, as disability care and support often require person-centred, individualised, and tailored solutions, the specific and complex needs of people with a disability mustn't be compromised by a 'one-size-fits-all' approach to the delivery of care and support.

NDIS pricing must reflect the actual cost of delivering services, particularly for specialised and high complexity supports, and services provided in regional, rural, and remote locations. Currently, geographic and systemic inequities disproportionately disadvantage participants in regional, rural, and remote areas.

NDIS pricing arrangements should include mechanisms to drive innovation and include flexibility for services to distribute costs across participants and programs that deliver high-quality, value-for-money solutions.

NDIS pricing models should include mechanisms to incentivise high-quality service delivery and enable innovation. There should be enough flexibility in the pricing arrangements to attract and retain highly skilled support workers and allied health practitioners and provide competitive wages that reflect the additional skills and experience required.

NDIS pricing mechanisms must be fair, ensure the viability and sustainability of the sector and ensure equitable outcomes regardless of location.

Detailed Issues and Recommendations

1. Equity of Outcomes and Tailored Pricing for Rare Diseases

Issue:

Rare disease participants often require intensive and specialised support due to the complexity of their disabilities and disability-related health supports. Current pricing mechanisms often fail to capture these complexities. NDIS participants with rare disease disabilities that have the cumulative and compounded combination of severe disability impacts, intensive behaviour support, and disability-related health supports require additional pricing adjustments.

Many providers are unable to meet these needs due to a lack of qualified staff and resources and the cost of intensive training and professional development to ensure quality services. The result is a shortage of suitable support and allied health services for NDIS participants living with rare disease disabilities.

Recommendations:

1. **Introduce a Rare Disease Complexity Loading:** Add a pricing adjustment for participants with conditions that require both high intensity behaviour support and specialised disability-related health supports.
2. **Reinstate the Level Three High-Intensity Support** category to allow providers to meet the duty of care and support needs of participants requiring higher-intensity services.
3. **Establish tiered incentives** for workers who complete specialised training, supporting skill growth in complex care areas that support rare disease participants.

> *"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."*

2. Provider Travel Arrangements for Regional, Rural and Remote Areas

Issue:

Thin service markets in regional, rural, and remote (RRR) areas make service delivery challenging and create severe inequities in service delivery for all NDIS participants, and this is only exacerbated for people with rare disease disabilities. Providers face disincentives to operate in these areas due to high travel costs, low participant density, and logistical barriers. When the participant also requires high-intensity supports due to their rare disease disabilities, this can create additional challenges.

The result is that NDIS participants in RRR bear the financial and emotional burden of accessing essential care and supports, as they often have to travel to access services in centres and clinics as they are not funded for place-based, person-centred mobile service delivery.

Where services can be delivered in situ at a person's home, the NDIS participants are subsidising the provider travel and non-face-to-face costs through their individual support plans, at the expense of their individualised therapy and direct person-to-person supports. This is because NDIS funding allocation in individual plans does not routinely include an uplift for provider travel and mobile service delivery.

RVA proposes an alternative model where provider travel and associated actual costs are invoiced to the NDIA directly for payment.

This will increase transparency and accountability, provide improved oversight by the NDIA to ensure value for money and remove barriers to service provision in regional, rural, and remote locations. It will also provide the NDIA with data capture regarding which providers are servicing locations including geographically remote locations.

Recommendations:

1. **Travel Cost Separation:** Manage travel costs independently of participant plans through a centrally administered *NDIS Provider Travel Fund*.
    - This ensures that participants receive their full allocation of supports without reductions for travel-related expenses.
    - Providers can submit their actual costs
2. **Regional Travel Loading**: Provide regional travel loading to support equitable service delivery. Ensure providers can claim:
    - Actual travel time and costs.
    - Accommodation for overnight stays.

"Participants are carrying the financial risk of travel costs, undermining their ability to access equitable outcomes. This burden must shift to systemic funding models."

"The solution is to separate provider travel completely out of plans so that all participants receive the intended number of hours for therapy or support, and travel costs are managed separately through agency or other government mechanisms" – RVA, Joint Standing Committee on the National Disability Insurance Scheme)

"Participants in regional, rural, and remote areas face limited provider availability, higher costs, and service gaps. Current pricing mechanisms place undue burdens on participants' budgets, particularly for provider travel, and offer little incentives for providers to support these NDIS participants."

3. Pricing for Workforce Sustainability and Innovation

Issue:

Current pricing models do not adequately incentivise innovation, professional development, or workforce retention. This stifles the ability to meet complex participant needs effectively.

The focus on activity-based funding, as applied in the healthcare and hospital funding models, can disadvantage people with complex and intensive needs who require longer appointments, therapy sessions, and supports to deliver equitable outcomes compared to non-rare disease peers. A focus on outcome-based funding focused on functional maintenance or limiting functional decline would benefit the rare disease disability cohort.

Workforce shortages, particularly in rural and remote areas, limit access to skilled care for rare disease participants. The workforce often lacks the specialised knowledge required to address the unique needs of this cohort and there are limited financial and pricing incentives for providers to invest in their workforce to build this capability.

Sustainable workforce pricing is essential for attracting and retaining skilled professionals. Existing NDIS pricing does not adequately reflect the costs of professional development, career progression, and advanced skills.

Recommendations:

1. **Professional Advancement Loading:**
   Incorporate a pricing adjustment for providers employing workers with advanced training or rare disease expertise.

2. **Supervision and Mentoring Support:**

   - Allocate funding within pricing arrangements for providers to employ supervisors who train and mentor less experienced workers, creating a sustainable workforce pipeline.

   - Provide additional shadow shift funding provisions for participants with intensive or very high support needs, including severe communication disabilities, disability-related health supports, and intensive behaviour support needs, where 6 hours of shadow shift support is insufficient to deliver appropriate care.

3. **Develop Cost Models** for all services including Support Coordination, Allied Health, and Behaviour Support practitioners along the lines of the existing Disability Support Worker Cost Model. This will improve transparency for providers and participants and enable comparison across providers who are delivering innovative solutions.

4. **Outcome-Based Funding**
   Explore models that fund providers based on participant outcomes rather than service hours delivered. Trial funding arrangements that incentivise improved participant outcomes (e.g., increased independence, reduced hospitalisations) or deliver high-quality interventions that align with participant goals.

5. **Alternative Commissioning/Transdisciplinary Regional Hubs**
   Develop pricing arrangements that enable alternative commissioning models, such as place-based service hubs staffed by transdisciplinary teams servicing NDIS participants, and Aged Care and Veterans affairs recipients.
   - These hubs can deliver multiple services during a single visit, reducing participant travel costs.
   - Where appropriate they can also deliver efficient, value-for-money solutions and reduce costly duplication of services for like-type support across disability and aged care participants.

"NDIS pricing must enable quality providers to operate while ensuring they can provide ongoing professional development training to meet client needs, regular debriefs with staff to ensure sustainability and wellbeing of the workforce, and to deliver their services across all locations. There need to be incentives to deliver services to NDIS participants with high-intensity support needs, high levels of health literate support, and intensive/complex behaviour support needs."

4. Data-Driven Reform for Rare Diseases

Issue:

The lack of detailed data on rare disease participants hampers efforts to design equitable pricing frameworks and address service gaps effectively. RVA continues to urge the NDIS to improve rare disease data recording and reporting and recommends that IHACPA also call for this data to be captured. This data can be used to inform pricing models for high-intensity and complex participants with rare disease disabilities, monitor provider service provision for this cohort, and ensure rare disease participants are receiving appropriately funded supports.

Recommendations:

1. **Co-Design with Rare Disease Experts:**
   Include rare disease representatives in the development of pricing models to ensure they reflect the lived experiences of participants.
2. **Rare Disease Data Collection:**
   Collaborate with NDIS stakeholders to improve data collection, including:
   - Tracking participants by rare disease diagnoses.
   - Monitoring disparities in service access and outcomes across geographic locations.
   - Enhance data collection on service delivery costs, especially for providers supporting people with rare disease disability and intensive and complex support needs.

3. **Enhance participant access to quality data.** Provide a public provider performance and rating scheme to enable participants to identify providers delivering value for money, innovative, and quality supports. This will enable service comparison and inform consumer decision-making, thereby improving choice and control.

> *"If we are not counting rare diseases, people living with rare diseases do not count."*
>
> *- National Strategic Action Plan for Rare Disease*

Conclusion

RVA commends IHACPA for prioritising equity and sustainability in its recommended pricing reforms. We remain committed to collaborating with IHACPA and co-designing to ensure pricing reforms reflect the unique needs of our rare disease disability cohort.

By incorporating co-designed and tailored recommendations, IHACPA can address systemic inequities, support workforce sustainability, and improve outcomes for NDIS participants with rare disease disability impacts.

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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 May 2024].