Standing Committee on Health, Aged Care and Disability

Inquiry into the Thriving Kids Initiative

Rare Voices Australia Submission

October 2025

About Rare Voices Australia

Rare Voices Australia (RVA) is the national peak body for the estimated two million Australians living with a rare disease, nearly all of whom experience long-term impacts daily – impacts that meet the Australian Government's definition of a disability. The disability impacts of living with a rare disease often aren't recognised by policymakers.

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, governments, key peak bodies, researchers, clinicians, and industry. RVA collaborates with over 100 rare disease groups/organisations in Australia that are consumer-led, not-for-profit groups and organisations. A complete list of RVA Partner groups/organisations is available on our website.

RVA advocates for the best outcomes for Australians living with a rare disease, and their families and carers.

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 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 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, 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". This includes the estimated 100,000 National Disability Insurance Scheme (NDIS) participants with severe and 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.

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. In keeping with the cross over between many rare diseases and disability, 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).

RVA also commissioned The McKell Institute's 2019 report, *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases (the Disability & Rare Disease report)*[2] which informed the Action Plan.

The Disability & Rare Disease report made seven recommendations (see Appendix 2). The *Disability & Rare Disease Report* identified that over 80 percent of people living with rare disease in rural Australia reported not having their health and disability care needs fully met, including over one in four people reporting that their needs for assistance were not met at all.

> *"Successfully navigating separate systems that are supported by a mix of commonwealth, state and private funding with services delivered by government, for-profit and non-profit providers requires detailed knowledge of each system."*
>
> *– The McKell Institute*

Rare Voices Australia's Submission

RVA welcomes the Australian Government's commitment to improving early childhood supports through the Thriving Kids initiative, recognising the potential benefits of foundational services for children with mild to moderate support needs identified through their level of developmental delays and/or autism. However, we join other advocacy organisations in expressing concerns about the design, rollout, and potential unintended consequences of this reform, particularly for children with rare and undiagnosed conditions.

RVA understands that the foundational supports provided through the Thriving Kids Program may encompass:

- Parent and carer coaching
- Peer support groups and navigation/key-worker roles
- Short courses for parental skill development
- Low intensity allied health supports (e.g. speech and occupational therapy) delivered in mainstream settings
- Enhanced access to early health and development screenings (e.g. new bulk-billed three-year-old Medicare health checks).

RVA acknowledges that maintaining a sustainable and responsible NDIS through the development of foundational supports is essential to continue the social licence for all programs to operate. RVA recognises that NDIS funding will remain available for severe, lifelong and complex rare disease disabilities, and the system's renewed focus on serving those with "significant and permanent needs" could, in principle, make the insurance framework more equitable and sustainable for those with the highest needs. Once the Thriving Kids initiative is fully operational, NDIS access and eligibility will be reformed so that children with mild to moderate support needs will no longer enter the scheme but will receive support through the Thriving Kids Program.

RVA is hopeful that early intervention programs under foundational supports programs such as Thriving Kids may offer faster, less bureaucratic access for children with emerging or undiagnosed conditions, potentially reducing the diagnostic 'gatekeeping' that currently delays supports.

Thriving Kids Program and Children with Rare Disease Disability

Children with rare diseases often present with developmental delays that are subtle, fluctuating, or atypical. Many children with rare disease disability will receive a 'global developmental delay' or 'idiopathic autism diagnosis' to explain their symptoms and functional impacts while they await further assessment, testing and interventions. It is therefore essential that the Thriving Kids Program recognise the specific needs and complexity of children with underlying rare disease disability who are awaiting genetic testing and/or specialist assessments, or for whom a diagnosis is not yet possible.

Families of children with rare or newly recognised progressive diseases may find themselves initially routed into the Thriving Kids foundational supports program, but soon discover those supports are inadequate as their needs escalate. The processes for escalating or ‘escalation criteria’ into the NDIS, and the evidence required, are not yet fully specified and risk creating new service gaps. It is critical that there is a streamlined pathway between the Thriving Kids initiative and the NDIS.

RVA is also concerned that families from culturally and linguistically diverse backgrounds, regional or remote areas, and those dealing with ‘diagnostic limbo’ or late-diagnosed children are most likely to fall through the cracks if NDIS access thresholds are tightened before foundational supports are established. Families in regional and remote areas may face additional barriers due to the limited availability of high quality and appropriately qualified service providers and risk being left out of foundational supports altogether. Furthermore, children with rare or undiagnosed conditions, who often present with varying and fluctuating needs, may not fit neatly into the new eligibility criteria and could be excluded from both Thriving Kids and the NDIS.

RVA also acknowledges the value of peer supports, especially for people living with rare disease disability who often feel isolated and face significant uncertainty about the prognosis and progression of their child’s condition given the lack of research and information about many rare diseases. When considering peer support, it is important that the Thriving Kids Program consider the peer support needs of families living with rare disease disability, while also noting that many RVA Partner rare disease groups/organisations are run by volunteers with limited capacity to provide extensive peer supports.

There are also concerns that the Thriving Kids Program may adopt a standardised model that doesn’t accommodate the individualised and multidisciplinary disability support required for rare conditions. Given the complex medical co-occurring conditions for children living with rare disease disability, RVA highlights the need for flexible, evidence-based supports delivered in familiar environments like homes, schools, and playgroups.

A family-centred model of support that considers a family’s capacity to access and implement the programs is critical, especially given rare disease families can often include several children with the same condition, or involve caregivers living with rare disease disability impacts themselves. RVA recommends that Thriving Kids also considers the needs of siblings and young carers.

Explicit engagement with paediatric experts, the rare disease sector and families living with rare disease disability in developing the Thriving Kids Program must occur to ensure there are tailored pathways responsive to rare and complex presentations. This co-design must consider the development of Medicare item numbers, referral pathways, the intersection with private insurance providers, and skilled workforce development and provider capacity.

Rare Voices Australia's Response to the Inquiry Terms of Reference

- **Evidence-based information and resources**

Given rare diseases often present with developmental delays that are atypical, RVA seeks to co-design culturally appropriate screening tools to assist parents and carers to identify if their child has mild to moderate developmental delays. These tools and supporting resources must include rare disease indicators (e.g., family history of known genetic condition, unexplained multi-system symptoms, dysmorphic facial features or congenital anomalies).

RVA is leading the collaborative development of the Rare Awareness Rare Education (RARE) Portal, Australia's growing national resource for rare diseases. The RARE Portal contains current, reliable and straightforward evidence-based information and resources for all rare disease stakeholders customised for the Australian context. The RARE Portal could assist parents to identify if their child has a mild to moderate development delay and support parents to connect with and provide support to these children.

The RARE Portal is increasingly being recognised and used by key rare disease stakeholders—including people living with a rare disease, governments, general practitioners, other healthcare professionals, researchers, peak bodies, industry, the National Disability Insurance Agency and others—as a renowned resource for rare diseases.

The RARE Portal has been funded by the Australian Government and is a key deliverable of the Action Plan.

RVA is also leading the development of the nationally co-designed *Rare Disease Disability Toolkit (*Toolkit*)*, a key deliverable of the Rare Disease Disability Project that is funded through the NDIS Peer Support and Capacity Building grant. The Toolkit will include rights-based self-advocacy information, tools, and strategies for navigating complex intersections between disability and mainstream/community supports, including for children with developmental delay. This project is funded until December 2026.

- **Workforce support and training**

Mainstream services often lack the flexibility to respond to the range of rare disease disability. RVA consistently highlights the limited awareness of rare disease presentations among educators and allied health professionals. Clear commitment and guidance on how to make reasonable adjustments to optimise access, participation and engagement in community settings and learning for this cohort are vital.

To deliver Thriving Kids effectively, the workforce must be equipped to recognise and support rare and undiagnosed conditions, and deliver flexible, family-centred care in familiar environments.

RVA maintains a comprehensive suite of online education and training resources tailored for families and professionals supporting people living with a rare disease, including families and carers. RVA's online education complements RVA's Education Program.

We encourage the Australian Government to engage RVA through a funded grant arrangement to co-develop and deliver rare disease disability awareness training for key frontline professionals, including maternal and allied health practitioners, early childhood educators, and General Practitioners (GPs). These resources will reflect lived experience and clinical expertise, be informed by RVA's Scientific and Medical Advisory Committee (SMAC) and our national network of over 100 RVA Partners (rare disease groups/organisations).

RVA has a proven track record of working with the Australian Government to deliver grants and the best outcomes for Australians living with a rare disease. For example, the Rare Disease Disability Project, *The Navigator Project* (see below for more) and the Rare Diseases – Awareness and Education grant, which are scheduled to end in 2026.

- **Seamless transition**

RVA is the lead consortium member on The Navigator Project, which is funded by the Australian Government's Rare and Complex Disease Telehealth Nurse Program and offers a strong model for the Thriving Kids initiative. This project is funded until 30 June 2026.

The Navigator Project demonstrates how to improve transitions across mainstream services, particularly in health, including for children with developmental delay and mild to moderate support needs. *The Navigator Project* includes three core components: the RARE Helpline, telehealth nurse navigation embedded within clinical (hospital) trial sites, and partnerships with consumer-led organisations.

Together, they deliver integrated, accessible, and data-informed support that empowers families, and builds capacity across systems. Importantly, the activities improve service navigation and help families of children with developmental delays access appropriate services without falling through the cracks. This model aligns with Thriving Kids' goals by centring lived experience, fostering cross-sector collaboration, and ensuring equitable access to care and support, including for families in rural and underserved communities.

The current focus on children under nine raises questions about continuity of care for older children with disability and their transition through mainstream systems. RVA seeks clarity on how foundational supports will be extended to children and young people beyond this age bracket recognising the permanent, lifelong impacts of living with rare disease disability.

The proposed Thriving Kids launch in July 2026, with NDIS access changes following in mid-2027, creates an inadequate window for system design, workforce development, and service establishment. RVA supports the sector's call for a longer rollout period, including genuine co-design, piloting, and evaluation phases.

Rare Voices Australia's Recommendations

1. **Rare Disease Priority Cohort**
   Children with rare disease disability are identified as a priority cohort within the Thriving Kids Program development, implementation and monitoring.

2. **Inclusion of Rare Disease Voices**
   The Thriving Kids Advisory Group must include representation from paediatric rare disease experts and families living with rare disease disability.

   RVA must be recognised as a national peak body and be engaged in genuine, sustained co-design to ensure:
   - Realistic and practical rollout, including piloting for children with rare disease disability.
   - Standardised national implementation to avoid jurisdictional inequities, especially in regional, rural, and remote areas.
   - Clear escalation mechanisms and transition pathways from Thriving Kids to the NDIS for eligible children with rare disease disability.
   - Development of screening tools and resources to help identify children with mild to moderate developmental delay associated with a rare disease.
   - That information, resources and programs are trauma-informed, multidisciplinary, and adaptable to the atypical and fluctuating needs, of children with rare conditions.

3. **Integration of the RARE Portal**

   That the RARE Portal, developed collaboratively by RVA alongside the rare disease sector and funded by the Australian Government, be integrated into the Thriving Kids Program as a trusted, evidence-based resource to support families, educators, and health professionals in identifying and responding to developmental delays linked to rare diseases.

4. **Funded Workforce Training Partnership**

   That the Australian Government engage RVA through a funded grant arrangement to co-develop and deliver rare disease disability awareness training for frontline professionals, including maternal and allied health practitioners, early childhood educators, and GPs through RVA’s online education.

5. **Targeted Navigation Functions**

   Invest in Models of Care that integrate disability navigation services with health, educational and community supports to ensure seamless integration and smooth transitions.

6. **Extended Rollout Timeline**
   Adjust the proposed timeline for a longer rollout period with genuine co-design, piloting, and evaluation phases including children with rare disease conditions and disability.

Conclusion

To ensure the Thriving Kids initiative delivers equitable, effective, and inclusive support for children with rare and undiagnosed conditions, the Australian Government must actively engage with RVA as the national peak body for Australians living with a rare disease. Doing so enables the Thriving Kids Program to leverage RVA’s extensive network, including our Scientific and Medical Advisory Committee, RVA Partners (rare disease groups/organisations) and the entire rare disease sector to facilitate genuine co-design.

This collaboration should go beyond consultation to include sustained involvement in program design, piloting, and evaluation, ensuring that the lived experience and clinical expertise of the rare disease community shape foundational supports.

RVA has the capacity to contribute our deep sector knowledge and connections to help build a responsive, flexible, and nationally consistent system that meets the needs of all children with developmental delay, especially those with rare disease disability and evolving conditions. A system where no child is left behind.

Thank you for the opportunity to contribute to this Inquiry.

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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

Recommendations - The McKell Institute, Disability & Rare Disease Report

The following are the seven recommendations from The McKell Institute report, *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases.*

Recommendation 1: Australia develops, endorses and implements a Rare Disease Strategy.

Recommendation 2: Australia establish a model of rare disease centres of excellence to address knowledge gaps and ensure all Australians with a rare disease have access to the best evidence-based care.

Recommendation 3: Australia introduce personal care plans to cover an individual's health, education and disability care needs. These overarching integrated care plans would allocate responsibility for the delivery of services to specific levels of government.

Recommendation 4: The Government centralise existing information on rare disease with a searchable database of information on rare diseases which health and disability professionals, patients and families, can access and inform.

Recommendation 5: Introduce mandatory training of relevant health and disability care professionals on the nature of rare diseases, effective management strategies, how to locate information and referral pathways to support and advocacy groups.

Recommendation 6: Urgent review of delays in access to equipment to ensure that NDIS participants receive approved equipment in a timely manner.

Recommendation 7: NDIA to incorporate a 'fast tracking review' category for people with rare diseases who have been identified as having permanent and significant disability. This would allow quicker access to additional supports when required through consultation with clinicians.

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 September 2025]

2. Jackson, A. The McKell Institute. *Disability and Rare Disease: Toward person-centred care for Australians with Rare Disease*. Oct 2019. 33 p. Available from: https://mckellinstitute.org.au/research/reports/disability-rare-disease/ [Accessed September 2025]