



**Attorney General's Department**

**Review of the  
Disability Discrimination Act 1992**

**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 are not 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 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 in Australia that are consumer-led groups and organisations. A complete list of RVA Partner groups/organisations is available on RVA’s 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 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 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”<sup>1,2</sup>. 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)<sup>3</sup>, 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 \(the Disability & Rare Disease report\)](#)<sup>4</sup> which informed the Action Plan.

The Disability & Rare Disease report (the Report) made seven recommendations (see Appendix 2). The Report identified that over 80 percent of people living with a 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 opportunity to contribute to the review of the Disability Discrimination Act 1992 (DDA). This submission is made in response to the consultation questions outlined in the DDA Issues Paper. It draws on lived experience insights from the rare disease disability community, including member organisations of RVA's Rare Disease Disability Network.

RVA strongly supports reforms that will modernise the DDA and ensure it is fit-for-purpose for all Australians living with disability, including those impacted by rare diseases.

People living with a rare disease disability often face unique and compounding forms of discrimination due to:

- Limited public and professional understanding of rare conditions
- Invisible or episodic symptoms
- Diagnostic delays and fragmented care
- Excessive self-advocacy burdens on individuals with rare disease disability and their caregivers
- Barriers to education, employment, and social participation.

## **Definition of Disability**

RVA supports modernising the definition of disability in the DDA to reflect the more contemporary understandings of disability and social and human rights models. The current definition uses terminology such as ‘malfunction’, ‘malformation’, ‘disfigurement’ and ‘disturbed,’ which don’t align with or reflect the lived experience of people with rare disease disability.

We support the inclusion of intersectionality in the DDA to reflect the lived realities of rare disease communities, as people with rare disease disability and their caregivers can experience compounding discrimination due to age, gender, ethnicity, or socioeconomic status.

### **Recommendation:**

1. The definition of disability be amended to:
  - be broader and more inclusive and remove deficit-based language.
  - explicitly reflect rare disease disability, including those with fluctuating, invisible, undiagnosed and/or cumulative or multisystem impacts.
  - expressly recognise intersectional discrimination, particularly where rare disease disability intersects with Aboriginal and Torres Strait Islander identity, mental health, socioeconomic disadvantage, and gendered caregiving roles.

## **Positive Duty to Eliminate Discrimination**

RVA supports the introduction of a positive duty for duty holders to proactively prevent discrimination rather than solely responding to complaints. The current complaints-based model places an unsustainable burden on individuals and carers living with rare disease disability.

A positive duty shifts responsibility to duty holders and reduces burnout among families navigating fragmented systems. This is critical for people with rare diseases who often face systemic barriers that are not addressed through reactive complaints processes.

Healthcare providers, education institutions, and employers should be required to assess and improve accessibility for people with rare disease disability.

### **Recommendations:**

2. Introduce a positive duty for duty holders to proactively eliminate discrimination and support inclusion, reducing reliance on complaints-based enforcement.
3. Develop clear statutory guidance for employers, educators, and service providers on how to meet this duty, with inclusion of rare disease-specific examples in training and resources.

RVA should be involved in the co-design of resources, including case studies, that speak to the specific needs of people living with rare disease disability.

## **Inclusion, Adjustments and Unjustifiable Hardship**

Many individuals and caregivers living with rare disease disability describe inflexible systems that fail to provide reasonable adjustments, especially in education, employment and healthcare.

Adjustments were often denied due to a lack of understanding of the disability impacts of rare disease or eligibility criteria based on well researched and recognised disability types.

RVA believes the duty to provide adjustments must be clarified and strengthened; and supports removing the term 'reasonable' and establishing a stand-alone duty to provide adjustments.

Adjustments must be flexible and individualised, and timely and responsive, especially in education, employment and healthcare settings, where rare disease impacts may be episodic, largely invisible or misunderstood.

RVA supports reforms that prohibit restrictive practices unless all other measures have been exhausted and documented. Families affected by rare disease disability report trauma from unsupported hospital and school settings where restrictive practices are used prematurely.

RVA supports amending the DDA to explicitly prohibit exclusionary discipline. Children with rare diseases disability are often excluded due to complex medical and/or behavioural and communication needs. National consistency in inclusive education support is essential.

Additionally, RVA supports reforming the concept of “inherent requirements” in the DDA to ensure it does not operate as a barrier to inclusion for people with rare disease disability. The current framework allows employers and education providers to make assumptions about a person’s capacity without meaningful consultation or consideration of adjustments. This disproportionately affects individuals with fluctuating, invisible, or progressive rare diseases whose abilities may not be immediately apparent. The general lack of awareness of rare disease disability impacts further compound this disadvantage, often leading to misinformed decisions and exclusion.

The Action Plan calls for integrated care and support that is person and family centred and the principle of equity of access. We recommend that unjustifiable hardship assessments mandate consultation with the person with disability to ensure their needs are understood and respected and considers the long-term benefits of inclusion and not just short-term costs.

### **Recommendations:**

4. Clarify and strengthen the duty to provide adjustments.
5. Require consultation with affected individuals before determining the ability to meet inherent requirements or claiming unjustifiable hardship.
6. Amend the DDA to explicitly prohibit exclusionary discipline and ensure consistent, inclusive education support across states.

## **Access to Justice**

Under the current DDA, the definition of direct discrimination relies on the comparator test. This test requires a person with disability to prove they were treated less favourably than a person without disability in similar circumstances, and that the reason for the treatment was because of their disability.

People with rare diseases often experience diagnostic delays, misdiagnosis, and fragmented care. Rare disease disability is often highly individualised in presentation and can be fluctuating in severity and impact.

This lack of diagnostic clarity makes it nearly impossible to identify a “comparator” in similar circumstances but without the disability. The comparator test assumes a level of diagnostic precision and standardisation that is fundamentally incongruent with the lived experience of rare disease. It also shifts the focus away from the actual harm or disadvantage experienced by the individual, and toward a hypothetical comparison that may not reflect reality.

RVA supports replacing the comparator test with a detriment-based test, which focuses on whether the person experienced unfavourable treatment because of their disability. This approach is more inclusive, trauma-informed, and aligned with the realities of rare disease. It would allow individuals to demonstrate the impact of discrimination without needing to construct a hypothetical comparator, while better reflecting the diversity and complexity of rare disease disability experiences.

### **Recommendations:**

7. Replace the comparator test with a detriment-based test which focusses on whether unfavourable treatment occurred because of a person’s disability.
8. Improve access for navigating complaints, including advocacy and legal assistance for people with rare diseases.

## **Offensive Behaviour and Vilification**

Stigma and misinformation about rare disease disability can lead to vilification, especially online. RVA supports the introduction of provisions to protect people with disability from offensive behaviour and vilification.

### **Recommendations:**

9. Inclusion of online platforms in the scope of protections.
10. Clear definitions and exemptions to balance freedom of expression.

## **Modernising the Disability Discrimination Act**

Futureproofing the DDA is critical to ensuring that it remains responsive to the evolving needs of people with disability, including those living with rare, complex, or undiagnosed conditions. As diagnostic technologies, social understandings of disability, and service systems continue to change,

the DDA must be flexible enough to accommodate emerging forms of disability and intersectional disadvantage.

**Recommendations:**

11. Ensure enforceability of Disability Standards, especially in health, transport, and education.
12. Establish mandatory minimum standards for Disability Action Plans, including consultation with people with rare disease disability and RVA as the rare disease disability peak body
13. Develop guidance materials tailored to rare disease disability, including case studies and best practice examples.
14. Require mandatory public reporting on accessibility and adjustments, including rare disease-specific data, to improve transparency and accountability.
15. Include a regular review cycle for the DDA, similar to the five-year reviews of the Australian Disability Standards, to ensure the DDA remains responsive to emerging needs and lived experience.

These recommendations align with the Action Plan’s call for sustainable systems and workforce, and the need to build rare disease knowledge, evidence, and expertise.

## Conclusion

People living with rare disease disability experience unique and compounding challenges that must be addressed through inclusive, proactive, and trauma-informed reforms to the DDA.

RVA urges the Australian Government to ensure that these reforms reflect the lived experiences of people with rare disease disability and their caregivers.

By embedding inclusive protections and recognising the unique nature of rare disease disability, the DDA can become a more effective tool for equity and justice. RVA supports futureproofing the DDA by adopting flexible, inclusive terminology that accommodates undiagnosed, fluctuating, and complex conditions common in rare disease disability.

As the national peak body representing people living with rare disease disability, RVA calls on the Australian Government to formally engage with us in the co-design of all changes to the DDA and its implementation. This partnership is essential to ensure that reforms are grounded in lived experience and deliver meaningful, lasting impact for our community.

We thank the Attorney-General’s Department for the opportunity to contribute to this review and welcome further engagement.

**Contact:**

***Fiona Lawton***

Disability Advocacy Manager

Rare Voices Australia

**Email:** [fiona.lawton@rarevoices.org.au](mailto:fiona.lawton@rarevoices.org.au)

## 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 [culturally and linguistically diverse] 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 [The National Disability Insurance Agency] 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

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2. Australian Bureau of Statistics. Disability, ageing and carers, Australia: Summary of findings. July 2024. Accessed from: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release> on 10 October 2025.
3. Commonwealth of Australia, Department of Health. National Strategic Action Plan for Rare Diseases. Canberra; 2020. Accessed from: <https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf> on 10 October 2025.
4. Jackson, A. The McKell Institute. Disability and Rare Disease: Toward person-centred care for Australians with Rare Disease. Oct 2019. 33 p. Accessed from: <https://mckellinstitute.org.au/research/reports/disability-rare-disease/> on 10 October 2025.