

Hon Amanda Rishworth MP, Minister for Social Services

Hon Bill Shorten MP, Minister for the National Disability Insurance Scheme

23 August 2024

Dear Ministers,

RE: Rare Voices Australia submission regarding the draft lists of National Disability Insurance Scheme Supports

Rare Voices Australia (RVA) is the national peak body for the estimated two million Australians living with rare disease disability impacts. This includes the estimated 100,000 National Disability Insurance Scheme (NDIS) participants with severe to profound disabilities due to their rare disease.

RVA acknowledges the transformational value of the NDIS in the lives of people with disability and remains committed to advocating for a sustainable NDIS. NDIS participants living with rare disease disability impacts are reliant on a functioning, transparent, and flexible NDIS for their daily, intensive support needs. RVA recognises that legislative reform is necessary to ensure a fit-for-purpose scheme. We have reviewed the draft lists of NDIS Supports underpinning the proposed amendments to Section 10 of the NDIS Act 2013. RVA understands that the creation of new 'transitional' rules, which cover what is and is not an NDIS support, are being proposed.

RVA appreciates the opportunity to contribute to this discussion and to reflect the deep sense of unease and concern expressed by Australians living with rare disease disability impacts. You can read more detailed feedback from RVA and our rare disease organisation partners in Appendix 1.

Rare Voices Australia strongly cautions against the use of narrow and prescriptive lists

While RVA supports increased clarity regarding what NDIS funding can be used for, the use of narrow and prescriptive lists in this complex disability ecosystem is problematic. **RVA strongly cautions against this approach for the reasons detailed below.**

- A prescriptive list of approved supports cannot deliver a flexible, innovative and responsive NDIS and immediately requires exceptions and 'carve-outs', leaving too many areas open for interpretation.
- Current reported cases of fraud and misuse of NDIS funds are unlikely to be curtailed by the development of complex lists.
- This approach does not seem to deliver cost-savings and cost-containment measures.
- In some cases, it appears that value-for-money mainstream alternatives are not a consideration at all.

Lack of time and planning for community/sector engagement and codesign to ensure the 'transitional' rules are appropriate

As these rules are the basis for what supports NDIS participants can be funded for, in addition to the services and products people will be permitted to purchase, this is particularly alarming. Additional concerns are detailed below.

- A three-week consultation period is completely inadequate.
- This approach to community and sector engagement lacks consideration of 'reasonable adjustments' for people with disability, and the many non-profit or volunteer organisations and groups that support the disability sector.
- Even with Easy Read and AUSLAN versions provided, people with disability may need additional time to contemplate the 'transitional' rules and formulate their responses. This is especially the case for people with intellectual disability, Aboriginal and Torres Strait Islander people, and people of culturally and linguistically diverse backgrounds.
- It is also unclear what engagement has occurred with people living in rural, regional, and remote areas and how the short time frame has permitted a fair, equitable, and inclusive approach.

RVA requests that a Stakeholder and Community Engagement Plan be published

In recognition of the government's rapid and complex reform agenda, such a plan would facilitate transparency and include a timeline of expected engagement activities. This plan will enable people with disability, and the broader sector, to plan and prioritise their activities and limited discretionary time. It will also allow for additional support for engagement and decision-making where appropriate.

There continues to be a lack of authentic co-design with the disability sector

While there is a promise of future engagement for the development of the permanent NDIS rules, there is no information regarding:

- When and how this will occur.
- How long the transitional rules will be in place.
- The review and monitoring processes that will be used to ensure people with disability do not suffer during these transitional periods.

RVA also notes that the draft lists contain significant assumptions that the State and Territory Governments will agree to fund and provide foundational, mainstream, and community supports for people with disability in a way that meets their needs. Yet, we currently have no assurance they will do so.

RVA would also like to reiterate that:

- In May 2024, we provided a submission cautioning the government against enshrining the Applied Principles Tables of Support (APTOS) in legislation.
- To date, the government has not responded to the NDIS Review.
- The Foundational Supports Strategy is in its infancy in terms of development with no timeline for implementation. Meanwhile, people with disability remain at risk of falling through the cracks, particularly at the intersection between disability and health.

Rare Voices Australia is seeking urgent confirmation that where no mainstream service exists or is not practically available, or foundational supports are not yet implemented, the NDIS will continue to fund these reasonable and necessary supports to ensure no person with a disability goes without essential support.

The above is particularly important given the arbitrary line that is often drawn between disability and health for people living with rare disease disability impacts.

Rare Voices Australia is deeply concerned about sections of the draft NDIS Supports List that refer to 'Mainstream Health' responsibilities that will not be considered NDIS Supports

Specific feedback and examples from RVA's rare disease organisation partners are provided in **Appendix A**.

Given the size and complexity of the cohort we represent, RVA strongly urges State and Federal Governments, the National Disability Insurance Agency, and the Department of Social Services to actively engage with us as the national peak body for Australians living with a rare disease, and the wider rare disease sector.

RVA continues to advocate for formal recognition and engagement as a Disability and Carer Representative Organisation to ensure the considerable and complex needs of people living with rare disease disability impacts are met.

Yours sincerely,

Nicole Millis
Chief Executive Officer
Rare Voices Australia