

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

Appendix A

In the limited time provided, Rare Voices Australia (RVA) has reviewed the draft lists of NDIS Supports. We also held a virtual roundtable engagement session in April 2024 where we heard concerns from our rare disease organisation partners about the proposed legislative changes. We share the following urgent feedback.

Urgent Feedback from Rare Voices Australia and Our Rare Disease Organisation Partners

- The draft lists are developed based on current NDIS operational guidelines and practice. It is unclear whether the lists have been informed by numerous decisions by the Administrative Appeals Tribunal (AAT), which has consistently overturned NDIS decisions.

We seek clarification that the lists have been informed by AAT and court decisions and determinations.

- The definition of daily living expenses used to determine what is not considered NDIS funded support does not appear to align with the recent Federal Court ruling—*Warwick v National Disability Insurance Agency* [2024] FCA 616 (12 June 2024). The ruling defined day-to-day living costs as, “those everyday expenses which are incurred in the course of living for the purpose of living.”

We seek clarification that the definition aligns with the Federal Court ruling.

- There does not appear to be a lifelong view of the value for money of some supports or the return on investment to reduce overall supports over time. For example, there is funding for essential household tasks that a participant cannot undertake because of their disability, including meal preparation and delivery, house or yard maintenance, cleaning, and laundry, but not funding for equipment or products that can replace person-to-person support needs.

A ‘whole of life’ view when determining value for money is essential when the NDIS is contemplating approving supports.

- Therapeutic Supports are included in the list; however, the description is focused on ‘capacity-building’, rather than ‘functional maintenance and management’. For many people living with a rare disease, the goal of therapeutic intervention is functional maintenance and management to prevent further functional decline. This is especially the case for people living with progressive, degenerative, and rapid-onset conditions.

RVA requests that the description for Therapeutic Supports be expanded to include for the purposes of functional maintenance and management.

- There is other terminology in the draft lists that should be standardised and simplified for clarity and consistency. For example, assistive technology is referred to as ‘equipment’, ‘assistive products’, ‘products’, ‘specialist products’ and ‘specialist

supports'. It is unclear what the different terms are intended to convey. The term 'specialist' appears in several areas and may be intended to convey that a support or service is 'disability-specific'. However, RVA cautions its use in general, as it may limit access to mainstream, non-disability specific products, services and supports.

RVA recommends language be standardised for clarity and consistency and to protect against unintended narrowing or limiting of access to products, services and supports.

- **The values of dignity, independence, autonomy, and self-direction must be given appropriate consideration.** Some goods and equipment that would foster these are excluded (e.g. smartwatches to provide emergency alerts, medication alarms, seizure monitoring, dishwasher drawers, and Bluetooth-enabled smart technology white goods that allow for independence).
- RVA is pleased that person-to-person supports continue, however, these supports should not be preferred over value-for-money alternatives that support independence, dignity, and privacy, and participant choice.
- There appears to be a preference for narrowing services and providers to those that are disability-specific and a drive to limit NDIS participants from accessing flexible and cost-effective mainstream and community services, thereby fostering segregation and reducing inclusion and connection. This is deeply concerning.
- What is 'evidence-based practice and research'? Who is doing it and how can RVA and our rare disease organisation partners collaborate with the National Disability Insurance Agency? How is evidence-based practice determined for people living with rare diseases when there may be very small populations? Our understanding is the NDIS Evidence Advisory Council will not be established until later this financial year, so processes will be needed to answer these evidence-based questions before then.

RVA urges the government to actively engage with the rare disease community to develop evidence-based support frameworks for NDIS participants living with a rare disease.

- How will the new 'transitional' NDIS Rules regarding NDIS supports be implemented? What guidance material will be provided for NDIS planners and delegates to assist in navigating areas where exclusions and discretion may apply?

RVA recommends that NDIS participants who have supports currently funded in their plans who may subsequently be excluded under the transitional rules be permitted to continue to use these supports for the duration of their plan.

- What avenues will be available to NDIS participants regarding the right to challenge decisions either in terms of seeking funding for supports or approval for funds expenditure?
- There are concerns that the narrowing of the definition of NDIS supports will stifle innovation and development of products and services in the disability sector as there is no assurance that they will be approved on the lists.
- There are significant concerns regarding the application of the lists in regional, rural, and remote locations and areas where there are existing thin markets, and a high risk of people with disability having considerable unmet need.
- Efficiencies that can deliver cost savings to the scheme such as the establishment of loan pools for equipment and assistive technology hire do not appear in the list, nor does funding for equipment rental/hire.

This should be remedied to ensure access to essential equipment while awaiting applications for replacements or repairs.

- Where exceptions do apply as the support is ‘solely and directly’ related to the person’s disability, what criteria will be used to determine this and what evidence will the participant be required to submit?

RVA recommends extensive training for NDIS staff required to implement these ‘transitional’ rules, including where discretionary decision-making or nuanced interpretations are required.

- What provisions will be made for education and coaching for NDIS participants if they inadvertently use their NDIS funds for supports that were previously available but are no longer considered NDIS supports?

RVA urges the government to adopt an educational approach for people adjusting to the new framework and limit sanctions and restrictions that can have longer-term implications for funding, independence and well-being.

Mainstream Health Interface

The draft lists of NDIS Supports state the following are the responsibility of mainstream health services and will not be considered NDIS supports.

RVA seeks urgent engagement with the government to ensure that the disability-related and life-sustaining needs of the estimated 100,000 NDIS participants living with rare disease disability impacts are not compromised under the new proposed framework.

- **Clinical treatment of ongoing or chronic health conditions**

RVA is urgently seeking advice from the government on what it considers to be the treatment of ongoing or chronic health conditions. Many rare diseases have chronic health co-morbidities, and distinguishing between what is disability-related and what is health-related is extremely problematic and in many cases impossible.

RVA supports the suggestion from the Disability Advocacy Network Australia (DANA) for the government and NDIS to apply a least restrictive approach and include rules presuming inclusion where it is unclear under which scheme the supports fall.

- **Time-limited, goal-oriented services and therapies provided after a recent medical or surgical event, with the aim of improving the person's functional status, including post-acute rehabilitation or post-acute care**

What is the cut-off when post-acute rehabilitation becomes functional recovery, functional maintenance, or capacity building? People with rare diseases may take significant time to regain function due to the multiple and complex disability impacts. The time taken may exceed what is considered appropriate time-limited support for people without rare diseases.

People with rare disease disability impacts can experience numerous and regular hospitalisations which of themselves (and separate from any medical/surgical events) can contribute to functional decline and deskilling requiring significant intervention to return to functional baseline. How will the NDIS determine what is related to the experience of hospitalisation and what is related to the medical or surgical event?

- **Any pharmaceutical**

What is the definition of a pharmaceutical product? RVA is aware that many people living with rare disease disability impacts require disability-related health supports delivered in accordance with allied health/nursing plans. However, we understand some products listed in these plans, such as stool softeners, enemas, thickening agents, oral swabs, and food preparation/storage/transport devices etc. are not approved by the NDIS as they are considered either pharmaceutical or mainstream products. RVA recommends that all products and equipment required in a disability-related health support plan be covered by the NDIS.

- **Any equipment or assistive technology prescribed as a result of clinical care, treatment or management from a medical practitioner delivered in the context of clinical care**

RVA is very concerned that assistive technology or equipment prescribed for the management of rare disease disability impacts may be excluded under the proposed transitional rules, despite being a direct result of the disability impacts of the rare condition.

Examples include:

- Seizure alerting and monitoring for people with intractable epilepsy and severe intellectual/communication disabilities who are unable to alert carers to their need for support.
- Augmentative and alternative communication (AAC), smartwatches, communication devices, and decision-making and cognitive support applications.
- Ventilation/suctioning support and cough assist machines and respiratory specialist services and prescribed ventilation (Bipap etc.).
- Air conditioning for climate control where an NDIS participant has a condition that requires temperature regulation but the person is unable to independently manage their temperature regulation or supports, including overnight.
- Trans-anal irrigation systems are required for complex bowel care due to severe and chronic constipation associated with muscular dystrophies and rare syndromes.

With respect to palliative care, RVA is concerned that essential supports will not continue to be funded and recommends the inclusion of the following description from the Applied Principles and Tables of Support (APTOS) in the 'carve-outs' to add clarity,

"In relation to palliative care, functional supports as part of an NDIS participant's plan may continue to be provided at the same time as palliative care services, recognising that supports may need to be adjusted in scope or frequency as a result of the need to align with the core palliative care being delivered through sub-acute health services."

Other concerns raised by RVA's rare disease organisation partners:

- 'Early Intervention' is not limited to children but should also be applied to late-onset and acquired disabilities in adults. This needs to be explicitly referenced.
- Vacation Care/Outside School Hours Care (OSHC) is a mainstream expense for children under 13 years. But for parents of young people with severe disability, that type of care can require specialist-trained support, and intensive support ratios, and may need to continue until 18 years of age. These are not mainstream costs but rather directly related to the disability impacts.

What provision is there for disability-specific services for vacation care/OSHC to be included in the list, or a government contribution to the additional disability-related childcare costs?

- Will personal care, disability-related health supports, and communication supports, including Augmentative and Alternative Communication (AAC) software or subscriptions to create communication-adjusted curriculum/learning tools for children receiving home-schooling, be included?
- Can the NDIS fund home repairs for property damage that occurs as a direct result of the disability impact/behaviours such as wall damage from motorised wheelchairs or property damage from intensive behaviours of concern?
- Will the additional costs of running a modified vehicle that was only purchased as a direct result of disability impacts be included?
- What is the definition of specialist sensory play equipment? Can participants purchase adaptive play equipment (e.g. adaptive swings) in rural/regional/remote areas where there is no community or place-based alternative?
- Will the NDIS fund furniture removal for disability-specific related medical and assistive technology, and storage costs when in temporary NDIS-funded medium-term accommodation?
- Will the NDIS approve membership costs associated with recreational sports, especially when disability-specific recreational sports costs can be much higher than mainstream participation costs? What about value-for-money membership of a swimming pool to access hydrotherapy supports?
- Do 'general conference fees' apply to disability-related training/conferences for peer/family/carer training for people with disability?
- Will the NDIS continue to fund employment assistance in specialised supported employment settings or business skills development costs to provide training to support microenterprise development?
- Can people who self-direct their supports continue to access short term accommodation/respite using mainstream accommodation – caravan park cabins, Airbnb etc. – instead of disability-specific respite centres?