

Draft lists of NDIS Supports

Submission to Department of Social Services

Angelman Syndrome Association Australia

August 2024



ABN 42 169 355 488

Angelman Syndrome Association Australia (ASAA) is the national not-for-profit volunteer organisation dedicated to providing systemic advocacy, support, and raising awareness of the needs of people and families living with Angelman syndrome in Australia.

About Angelman syndrome

People with Angelman syndrome (AS) are renowned for their personality and charm, their life-affirming hugs, and their ability to brighten any room they enter. They are effusive with their affection and demonstrate a resilience and courage that humbles everyone around them. This courage is demonstrated daily in the face of adversity. When surrounded by people who care, who help them access regular health services and who foster their social connections and relationships, people with Angelman syndrome live rich lives and thrive in their community.

Angelman syndrome is a rare neurogenetic condition with significant impacts on all body systems. Impacts are severe to profound across all functional domains. In some cases, the hereditary nature of Angelman syndrome means there may be 2 or more family members with the condition.

The condition often presents first with seizures in infancy but missing developmental milestones is always a trigger for further investigation. It can be life-limiting due to severe intractable epilepsy. The associated sleep disorder is severe and is a direct cause of carer exhaustion.

People with AS require 24/7 intensive care and support from a trained workforce throughout their lives. They often require disability-related health supports, have complex communication needs, have challenges with emotional regulation and behaviours of concern, and research has recorded significant levels of carer strain and burnout¹.

There are progressive co-morbidities that can seriously impact health and disability as a person ages including dysphagia (choking), complex bowel issues and permanent bowel damage, scoliosis, and later onset and progressive motor coordination disorders (non-epileptic myoclonus, dystonia) and worsening seizure profile.

There are over 500 NDIS participants who live with Angelman syndrome, who receive considerable reasonable and necessary funded supports, and require lifelong person-to-person care and support.

For more information please contact:

Fiona Lawton

National President, Angelman Syndrome Association Australia

Partner Submissions

ASAA is a member of the Down Syndrome Australia (DSA) Disability Representative Organisation (DRO) consortium, representing people with intellectual disability and chromosomal variations.

ASAA appreciates the importance of commenting on the draft lists for the National Disability Insurance Scheme (NDIS) Supports related to section 10 of the National Disability Insurance Scheme (Getting the NDIS Back on Track No. 1) Bill 2024 ('NDIS Amendment Bill').

We are disappointed with the extremely short consultation period which has meant ASAA has not been able to consult effectively with community members on the proposed lists. In preparing this submission we rely on our understanding of the needs of people with Angelman syndrome, how they typically use their NDIS funding, and concerns submitted directly to ASAA regarding the proposed lists.

ASAA commends the [DROs Joint Submission on the draft lists of NDIS Supports](#), provided by Disability Advocacy Network Australia (DANA), and we reiterate the key asks:

1. Adopt a principles-based approach: The proposed lists will have a negative impact on people with disability. A principle-based approach will allow people with disability and their families to continue using innovative and cost-effective solutions to live their lives within their communities.

The key principles we believe must be included for NDIS supports are:¹

- Reasonable and necessary
- Be related to a person's disability
- Take into account what is provided by other government supports
- Represent value for money

Additionally, any changes must:

- Do no harm
- Have clear exceptions process and reviews
- Promote inclusion in the community.

2. Provide an extension for consultation: People with disability and DROs need time to meaningfully engage with their members and communities, and to fully examine the extent of both benefits and risks of the lists. The list needs the expertise of people with disability at the forefront and centre of their development and implementation.

¹ These principles are based on some of the existing rules: <https://www.ndis.gov.au/understanding/supports-funded-ndis/reasonable-and-necessary-supports>.

3. Provide clarity and assurances on exceptions and reviewable decisions: Policies pertaining to exceptions and reviewable decisions must both be firstly developed in consultation with people with disability, and secondly made available in accessible formats. While we oppose the lists, ensuring people with disability can contest.

ASAA is a partner organisation of Rare Voices Australia (RVA), the national peak body for the estimated two million Australians living with rare disease, and the estimated 100,000 NDIS participants living with rare disease disability impacts. ASAA supports the [RVA Submission on the draft lists of NDIS Supports](#).

ASAA specifically notes the following:

- We seek clarification that the lists have been informed by AAT and court decisions and determinations.
- We seek clarification that the definition of 'daily living expenses' aligns with the Federal Court ruling - *Warwick v National Disability Insurance Agency* [2024] FCA 616 (12 June 2024).
- A 'whole of life' view when determining value for money is essential when the NDIS is contemplating approving supports.
- We request that the description for Therapeutic Supports be expanded from 'capacity building' to include 'for the purposes of functional maintenance and management'.
- 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?
- RVA recommends extensive training for NDIS staff required to implement these 'transitional' rules, including where discretionary decision-making or nuanced interpretations are required.
- 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.
- 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.

ASAA Submission

The Angelman syndrome community has raised the following concerns regarding the lists:

- 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?
- 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?
- 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?
- 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?
- Will period underwear for girls and young women with severe intellectual disability be excluded as menstrual products, even when they require continence aids on a daily basis?

Community Quotes

"If our kids aren't able to attend normal vacation care then how we supposed to work? I certainly can't afford the cost of the disability service vacation care programs. I don't earn enough to cover them. And also can't afford to take leave every holidays."

"Very prohibitive for carers to return to work, in addition to the carer fatigue of managing our Angels without respite during these periods..."

"What about training and support of family members on alternate communication?"

"So this means period underwear is out - something our girls need due to their disability?"

"Vacation and after-school care - where angels require a higher level of support that is not the standard rate of usual "parental responsibility" and after age 12 should be covered. Otherwise how else can carers work? I don't understand how else this could be covered?"

"How can they possibly put a line on what is work specific vs disability related work supports here when, if there is any chance of our complex PWD's having employment, the entire experience from beginning to end requires high-level supports? How will this be nuted out?"

"Parental responsibility' for their loved one is a given and the Family Law Act 1975 (Cth) clearly defines what that includes. However, NDIS often confuses this with 'parental

capacity' to be all things to a loved one (or loved ones) with disability. In considering parental capacity we must take into consideration the physical and practical nature of the care requirement for someone with a severe to profound neurological condition.

In many cases there just aren't enough hours in the day to provide essential care and support for someone with Angelman syndrome (and similar rare diseases). Primary carers leave the workforce, often for long periods to care for their loved one, carer strain and mental health issues are real and well-documented, and mainstream connections with health, early childhood, and education are exhausting due to the fractured nature of the current systems.

Carer support is critical and is seriously lacking through the underfunded Carer Gateway and partner organisations. Families must be at breaking point or breakdown before time-limited crisis support is available."

"Young children with AS are often denied support worker funding as the NDIA classes their care needs as 'parental responsibility' due to their age, but their needs are not remotely comparable to their same-age peers. Their complexity means they can rarely be cared for by family members, friends or other informal supports, or safely attend early learning or before and after school care. Without adequate support worker funding, their high needs absorb all their parents' time, attention and energy at every waking hour, including during the night. It becomes nearly impossible for parents to care for their other children, cook, clean or leave the house, let alone return to work, exercise or socialise.

Even when funded, finding a suitable support worker is challenging and training them in the child's unique and complex needs is time-consuming. A support worker for a child with Angelman Syndrome needs to be fit and strong, trained in manual handling, first aid and seizure management at least, willing to manage nappies, toileting and difficult behaviours such as biting, and be observant, intuitive, mature, engaging, energetic and extremely patient."