



25 August 2024

Australian Government
Department of Social Services
By email: NDISConsultations@dss.gov.au

RE: Consultation on draft lists of NDIS supports

Deafness Forum Australia is the national consumer representative body for the 4 million Australians who live with hearing loss or ear or balance disorders, people communicating using Australian Sign Language (Auslan), and their families and supporters.

Deafness Forum collaborates with a broad range of specialised organisations within the hearing and disability sector, including early intervention agencies like The Shepherd Centre and Next Sense, citizen representative organisations such as Aussie Deaf Kids and UsherKids Australia, and community groups including the Auslan deaf community. We also have strong connections with primary research institutions and are involved in systemic advocacy and health initiatives, including the Hearing Health Roadmap (2019).

Deafness Forum Australia is committed to supporting the Government across the reform of the National Disability Insurance Scheme and shares the Government's vision of a financially sustainable NDIS to support future generations. We are, therefore, disappointed at the short turn-around period for consultation on the section 10 lists of NDIS inclusions and exclusions, and flag that we have had limited capacity to seek feedback from organisational or individual members.

We had previously written to the Department of Social Services emphasising the need to work in genuine co-design with the disability community and the Disability Representative Organisations that advocate for them.¹ The limited consultation period, combined with the delay in the provision of Auslan resources to facilitate the engagement of people who use Auslan as their primary language, falls short of our expectations of genuine co-design. We are also concerned that amendments were introduced specifically related to the s.10 lists which we have not had the capacity to review.

These are our recommendations:

Recommendation 1:

Deafness Forum supports calls for an extension of the public consultation for at least four weeks, to provide Disability Representative Organisations with the opportunity to fully understand how s.10 is intended to operate and seek feedback from the disability community.

Recommendation 2:

Deafness Forum respectfully asks that a standing NDIS Codesign Consultative Committee be established as a matter of priority, consisting of representatives from the Department, the National Disability Insurance Scheme, and Disability Representative Organisations to develop agreed principles for codesign across future consultation processes.

Recommendation 3:

The prescriptive lists should be scrapped. Prospective supports should be determined using a principles-based approach, with an emphasis on flexibility, responsibility, accountability, adaptability, and the participant's overall aims, values, and needs. lists should be scrapped. Prospective supports should be determined via a principles-based approach with an emphasis on flexibility, responsibility, accountability, adaptability and the participant's overall aims, values and needs.

Having defined principles would ensure that all future codesign processes are conducted fairly, avoiding further frustrations for both the Government and the disability community.

Lists should be principle based, not specific

Deafness Forum Australia is deeply concerned by the specificity of the lists, mainly the list of exclusions.

As far as we are aware, the lists were not constructed with input from people with lived experience of deafness or hearing loss, their families, or hearing health professionals and the National Disability Insurance Agency mostly disregarded what little input we were able to provide in the limited time available.

It's black and white, the Government is saying you can spend money from your plan on this, you can't spend your money plan on this. Australian taxpayers are trusting NDIS participants to do the right thing with Australian taxpayer dollars, not to get a free lunch, to use, abuse or have anything else more than what we are supposed to have... when it comes to Auslan interpreting, training, hearing aids, cochlear implants, technology, captioning, for that to be cut depending upon what people who are not Deaf or hard of hearing think is appropriate for us, I think that's inappropriate.

Consultation participant, DFA online consultation, 20 August 2024.

Through consultations with our NDIS Citizen Advisory Committee and other key stakeholders, we have identified at least several items or services that were either expressly excluded or not provided in the funded supports list, including hearing aid and cochlear insurance, essential iPads, smartphones and smartwatches, visual home security systems, strobing fire alarms, specialised visual doorbells, and subscriptions to captioning services that are considered fundamental and necessary supports for people who are Deaf or have hearing loss.

For independence and safety in my own home (my NDIS goal) I need a visual alert on my ovens, cookers and washing machine. I don't just want one. As older people with hearing loss are more likely to go into aged care facilities earlier than the average it is essential for my independence. (I live alone) not leave the washing in the machine, not burn my food, not leave my iron on etc.

- DFA NDIS Citizen Advisory Group Member,

These items and services are crucial for addressing the communication needs of many people who are Deaf or have hearing loss. Items such as smartphones and smartwatches address the communication needs of people who are Deaf or hearing impaired across all areas of life, including at work, school, home and in the community.

Specialised items like fire alarms and visual security systems allow people who are Deaf or have hearing loss to live safely in their homes. Our advisory committee raised the issue of prohibitive costs of purchasing items without NDIS funding, with one member stating:

I'm up for \$1600 for a new iPhone and a new iPad, and then I'm going to need new hearing aids. Before the NDIS I used to pay thousands and thousands of dollars for them, and then the NDIS came in... I'm looking at up to \$10,000 for essential equipment. I can't be involved in this [consultation] I can't talk to my grandchildren in Melbourne, I can't do so many social things without this technology... and now I don't work... I was 62, a woman with a disability, I haven't had a job since.

That technology, the communication devices that for everyone else is 'Oh yeah, that's a bit extra, we can fiddle on our phones we can play with Facebook', no Facebook is my connection, my only, sometimes my only connection to people. I usually live by myself, so it really is. It's not an extra.

Consultation participant, DFA consultation 20 August 2024

Some advisory group members have been able to access these supports in their plans, with the support of hearing health professionals, and spoke to how these supports had enhanced their independence, their capacity to work, and their capacity to attend school or participate in the community.

One group member advised that she routinely connected her mobile phone as a microphone to her cochlear implant to hear conversations during work meetings. Another group member, a teacher, described how hard of hearing high school students are routinely instructed to use their mobile phones as remote microphones for their cochlear implants or hearing aids in class.

It's important to note that mainstream devices like smartphones, iPads, and smartwatches are not only widely available and easier to service but also more affordable than specific assistive technology devices. In some cases, using such widely available devices can substitute for hard-to-access AUSLAN interpreting services or live captioning.

We understand that all participants will have their plans reassessed as part of the transition to the new supports framework. However, it's crucial to note that the exclusion of such devices from the new lists would be in disregard of clear expert evidence that these supports are necessary to address the disability-related needs of individuals.

The support categories are vague and difficult to interpret

Many of the support categories that the NDIS will fund are vague and difficult to interpret. Gaps in the descriptions raise questions about what people can or can't access under specific categories.

Our advisory group was particularly concerned about the provisions relating to interpreting and translation. We strongly advocate for clearer and more inclusive provisions that go beyond funding only 'essential personal, social or community activities' where translation is not available from a mainstream service.

What isn't essential? Everything is essential.

Consultation participant, DFA consultation 20 August 2024.

'When it comes to social events, does that mean that church isn't necessary, family events aren't necessary, significant celebrations? One deaf friend told me that they were told that they were naughty for organising an interpreter to do something social like talking to a hairdresser about the type of haircut they wanted... it's going to be a 'funnel' who will decide or define what the funnel is, and what it is not, what gets through the funnel and what does not? For Deaf people, we just want to have a fun life, a social life, like everyone else'.

Consultation participant, DFA consultation 20 August 2024

It is also unclear whether live captioning, would be considered an interpreting or translation service, noting that many of our members use live captioning services to support them to participate in both face-to-face and online meetings.

Others expressed confusion when specific supports were not provided in the descriptions. A member with a Lions Hearing Support Dog questioned whether the necessary ongoing training of her support dog would be provided as NDIS-funded support or whether she would need to fund this cost herself.

We are not convinced that adding arbitrary constraints on the capacity of planners and participants to determine the funded supports and services that meet an individual's specific disability-related needs will stop the multifaceted and highly complex issue of inappropriate spending of NDIS funds. There is no simple solution to this problem, and it will be impossible to create a definitive list of supports and services that cover the legitimate disability support needs of all participants.

We strongly advocate for the retention of a principles-based approach to determining funded support. This approach, rooted in decision-making based on general concepts and values, provides a solid foundation for the NDIS.

Key principles already exist when determining whether to approve or deny a prospective support, including:

- That the support is reasonable and necessary
- That it is related to a person's disability
- That it is not (currently) provided by other government supports, and
- That it represents value for money¹

Deafness Forum Australia supports the recommendation by the Australian Federation of Disability Organisations (ADFO) to additionally apply the following general concepts and values:

1. **Focus on Broad Guidelines:** Provide broad guidelines or fundamental principles that set the overall direction for decision-making.
2. **Flexibility:** Allow flexibility in interpreting and applying principles to various situations where not every possible situation can be anticipated.
3. **Encourage Judgement:** Apply judgement in how to best adhere to the principles, fostering a sense of responsibility and accountability.
4. **Adaptability:** Allows adaptability to changing circumstances more easily than a rule-based system.

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

5. **Holistic Focus:** Encourage a broader view of issues, considering the overall aims, values, and needs, rather than focusing narrowly on compliance with specific rules.

NDIA staff, plan managers and self-managed participants should receive ongoing education and training to understand and apply these principles and concepts. Self-managed participants, as integral decision-makers, should have access to timely personalised and informed advice to support them in making decisions around prospective funded items and supports.

Disability service providers should also be held accountable for ensuring that the supports and services they provide are accurately described, evidence-based, and fit for purpose. Predatory business practices such as overpricing, overservicing, and the use of high-pressure sales techniques to induce self-managed participants to use their plan funds need to be addressed as a matter of priority.

Additional Concerns

Appeal options must be retained

Participants must retain the right to apply for a review of the supports and services they are eligible to receive under their plans. Review processes should be easy for participants to access, provide for a timely determination, and allow for external review if a participant remains dissatisfied with the NDIA's response

Timely processes for varying participants' support needs must be provided

Participants' support needs can vary both as a direct consequence of their disability or on account of external factors, such as a sudden and unexpected change in functionality or damage to existing assistive technology. Participants must have the capacity to easily apply for a variation of their personalised supports and services, with the guarantee of an expedient response from the NDIA

Participants cannot be disadvantaged while the Australian Government, States and Territories negotiate responsibilities for supports and services

We understand that it will be some time until the states and territories will be in the position to step up to the responsibility of providing supports and services for people with disability via foundational supports. However, the urgency of this matter cannot be overstated. It is critical that this transfer is handled carefully to ensure that people who are Deaf or hard of hearing are not left without the supports and services they need.

State and territory services have been severely eroded, and it will take time to re-establish them. For example, we have heard anecdotal reports that Auslan services are rarely available in NSW and Victorian hospitals, police stations, courts, audiology clinics, and eye surgeries since the introduction of the NDIS, with speculation that this is because interpreters can charge higher rates through the Scheme.

Concluding comments

For many years deaf and hard of hearing people were isolated. We all know about the Christmas lunch syndrome, the dinner table syndrome... every day of the year. I now have an interpreter for family events, Christmas celebrations and other significant events. For the first time in my life, I actually feel included.

Consultation participant, DFA Consultation, 20 August 2024.

Deafness Forum Australia appreciates that the Government is accountable to Australian taxpayers to ensure that NDIS funds are spent as originally intended - to fund reasonable and necessary supports for people's needs that arise directly from their disability.

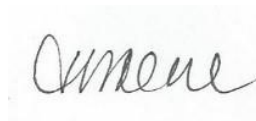
We understand that inappropriate spending of NDIS funds must be addressed. We also acknowledge that the current mechanism for determining support can be confusing for NDIA staff, planners, and participants and drives inconsistent outcomes for participants.

However, for the reasons we have detailed in this submission, we cannot support the draft lists as the solution to these problems, even on an interim basis. There is no 'one size fits all' across the disability community, or as one of our NDIS Citizen Advisory Group members put it '*someone else's want could be my need*'. A principles-based approach, with appeal rights, is the fairest way to ensure that all people with disability get access to the reasonable and necessary disability related supports they need.

Deafness Forum Australia welcomes any questions the Department may have and does not require confidentiality for this letter, which can be publicly available.

We thank you for the opportunity to comment.

Yours sincerely,



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ⁱ Deafness Forum Australia, *Submission to the Inquiry into the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024*, submitted 12 July 2024.