**Feedback on Draft NDIS Support Lists.**

The following submission was prepared by Deafblind Australia with input and assistance from a number of organizations representing Deafblind people, their families and the professionals that support them. We extend our profound gratitude to the following organisations for their support and contributions:

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**About deafblindness:**

Deafblindness is a unique and isolating sensory disability resulting from the combination of both hearing and vision loss or impairment that significantly impacts communication, socialization, mobility and daily living.

The term ‘d/Deafblind’ refers to people who have some hearing and vision, as well as people who are completely deaf and blind. It is difficult to accurately state the incidence of deafblindness in the community due to the broadness of the classification and diversity of conditions the term captures. Based on data from the Survey of Disability, Ageing and Carers deep dive 2018 the number is thought to be around 200’000 although this is likely an underestimate. This likelihood is due to the fact that many people with dual sensory impairment do not identify as such and may not report this status and because the SDAC does not cover remote regions and thus does not reflect the high rates of sensory loss/es in First Nations communities.

The Deafblind community is very diverse. Its members have varying degrees of vision and hearing impairment and come from diverse cultural backgrounds. Some live with multiple or complex disability.

**Key feedback:**

* Little in the lists gives much hope that the issues Deafblind people report when accessing the scheme and the supports/equipment they need will be resolved or reduced following their introduction.
* The lists attempt to compartmentalize people’s needs to allow them to be delegated more easily, from an administrative point of view, to different funding streams and domains of responsibility. Health, disability, mental health and a host of intersectional factors cannot be separated in this way and any attempt to administer supports along these lines is doomed to exclude and overlook the valid needs of many.
* There is much potential for people to be denied supports they need and that are more cost effective because of the subjective application of these lists by staff.
* Exclusion of mainstream devices and equipment is not only likely to push participants towards devices that are not appropriate for their needs, but towards solutions and equipment that will be more costly in terms of the product itself, training and ongoing support and maintenance. This will have the exact opposite effect desired by the architects of these reforms in terms of both participant outcomes and scheme sustainability.
* The accessibility and timing of this consultation was not reasonable, and unfairly marginalises several key stakeholder groups including Deafblind people.  Serious delays in the provision of EasyRead and Auslan translations further exacerbates the impacts of what is already an incredibly tight timeframe for turnaround. There are a number of organisations represented in this submission who, given sufficient time and resourcing, are able to support the production of these alternative formats as well as local tactile interpretation for those who require it. DBA implores DSS to reconsider its timelines, engagements and approach to these consultations in order to ensure they yield comprehensive, quality insights by being open to the broadest range of impacted stakeholders possible.

**Detailed feedback and concerns- Supports that are NDIS Supports:**

* Assistance to Access and Maintain Employment or higher education. Description: *“Workplace assistance that enables a participant to successfully obtain and/or retain employment in the open or supported labour market, including individual employment support, employment preparation and support in a group and school leaver employment supports to assist transitioning from school to employment.”*

Why does the descriptor of this category not mention anything about accessing higher education? This needs to be amended to avoid confusion.

* “*Does not include: learning and support needs of students that primarily relate to their education and training attainment.”*

It is concerning to see the lack of acknowledgement of the impact of disability support provision on academic performance embedded in this carve out. There are cases where student’s academic attainment is severely limited or influenced by the quality of support provided in an academic setting. For students with dual sensory loss, this starts in primary school due to the critical lack of a visiting teacher service for deafblind students. This carve out seems to mean that a Deafblind student could use their plan for interpreting services, but not for tutoring or other academic support. Given what we know about issues accessing quality Auslan interpretation it is highly probable for a student to have academic support needs directly impacted by the quality of their support provision. If a student needs extra help because they are accessing the classroom via sub-par interpreters and any available online help or resources are in another language then this is an academic need that arises from a disability specific set of causes.

DBA has also heard of the frequent tension between students and institutions regarding who is the responsible party for sourcing and paying for student supports. It is difficult to see this situation improving after the introduction of these lists. A representative from CHARGE Syndrome Australasia also provided the following reflection:

*“Learning a trade is problematic for people with complex communication and sensory needs. Our experience with TAFE related to my son wanting to learn a trade - an electrical test and tagging course. This was denied by TAFE as the lecturer cited communication difficulties between student and teacher would make it a high risk environment (how could the lecturer understand what the student knew if their speech was hard to understand?). At the time, TAFE would only provide an interpreter, not a support worker. Son is still keen to do the training, but will need a comm guide, which is not provided currently.”*

* Assistive Equipment for Recreation. Description: *“Specialist products used in competitive and non-competitive sports and other recreational pursuits.”*

DBA remains concerned as to how the determination around what constitutes “specialist” equipment in this context is made and who is making that determination. Is the mechanism of definition the qualities and nature of the product itself or the context in which it is used? Where would this leave, for example, a tablet that a participant uses to display digital sheet music in large print whilst they play the piano?

* Assistive Products for Household Tasks. Description: *“Specialist products to enable cooking, cleaning, washing, home maintenance and other tasks.”*

DBA remains concerned as to how the determination around what constitutes “specialist” equipment in this context is made and who is making that determination. DBA is also concerned these lists will create the same subjectivity and inconsistency among plans that these and other changes currently before the sector are supposed to minimize/avoid entirely.

* Assistive Produces for Personal Care and Safety. Description: *“Specialist products for personal care or safety including beds and pressure mattresses, toilet and bathroom equipment, specialised clothing and continence needs.”*

Along with the already flagged issues relating to definitions of “specialist”, attention needs to be paid to the place of smart devices in this category especially from a safety point of view.

* Communication And Information Equipment. Description: *“Products to assist with alternate communication or to access written or spoken communication via electronic or other means.”*

It is good to see the word “specialist” is not used in this description as it is in other domains. This provides the broadest scope for cost effective and fit-for-purpose solutions across a wide range of contexts and should be carried over into other descriptors throughout this document.

A representative from Deafblind West Australians adds:

*“As a deafblind person, I use an iPhone to help me with this. It
integrates with many programs and apps, it has many accessibility
features which are customisable, and it is easy for the other person in
the conversation to use if I need assistance (this last part is key).”*

* Community Nursing Care. Description: *“Provision of specialist care for participants who have high care needs requiring a high level of skill, and for the training of support workers to respond to the participant’s complex needs.”*

Funds for training of support workers is a consistent issue among many Deafblind people. However, there remains room for subjective definitions to render these supports off limits to those who may benefit from them. What is the working definition of ‘complex needs’? How is this complexity measured/defined and by who? Does it only recognise medical complexity? What about complex communication needs? DBA also foresees future tension around who is responsible for funding the training of support workers in different contexts. For example, who would be responsible for the upskilling of support workers necessary for a deafblind child to attend their local primary school?

* Development Of Daily Care and Life Skills. Description: *“Development of daily living and life skills focuses on training and development activities undertaken by a participant or their carer to increase their ability to live as autonomously as possible, including supports that will enhance the ability of the participant to use public transport independently.”*

It is vital that the importance of language and communication as a life skill is acknowledged in this domain. Funds for families to learn Auslan as part of creating a language environment in the home that is accessible to their child, for example, must be considered here.

* Hearing Equipment. Description: *“Specialist supports (excluding surgical services) where these supports directly relate to a person’s permanent impairment.”*

DBA is concerned again as to how the application of “specialist” will look in practice. This reads as though hearing aids would be considered an NDIS support but noise cancelling headphones the same person might need for ZOOM calls/remote work are not covered despite the need for each arising from the person’s disability. How will this nuance be captured/reflected in the application of these lists?

* Home Modification Design and Construction. Carve outs that are not NDIS supports: *“Design and subsequent changes or modifications to state or territory owned public housing.”*

This separation has concerning implications for consistency nationally. AIHW data shows that at June 2022 36% or 1 in 3 social housing households had at least one person with a disability. Given the prevalence of disability among public housing residents it warrants some consideration/involvement/direction from the agency if the end goal in mind is a system where people’s access to supports is nationally consistent.

* Household Tasks. Description: *“Essential household tasks that a participant is not able to undertake because of their disability, including meal preparation and delivery, house or yard maintenance, cleaning and laundry.”*

Given the commensurate emphasis on removing ‘everyday items’ from the scheme, DBA is concerned that planning decisions in these domains will ultimately lead to in-person supports being referenced over equipment even when these supports are more difficult to access and more expensive. We have heard from a Deafblind community member about their request for rechargeable hearing aids being rejected and instead being offered increased funding for support workers to come weekly and change their old hearing aid batteries at a cost over the life of the plan of 5 times that of the new aids requested.

* Interpreting and Translation. Description: *“Assistance to a participant to enable independent communication in essential personal, social or community activities where translation is not available from a mainstream service.”*

DBA is concerned with a number of details in this description. What mainstream service currently provides translating and interpreting services? TIS? NRS? This reads like an attempt to remove some of the responsibility for funding interpreting into other jurisdictions and risks creating confusion over who is responsible for sourcing and funding interpreting support. This is already an issue among Auslan users nationwide and hence any policy that seems to intensify this confusion is concerning. It is also foreseeable that current tensions around defining “reasonable and necessary” or “exceptional circumstances” would also extend to definitions of “essential”. Who determines whether the personal, social or community activity for which the support is requested is essential, and what criteria will be used to make this determination?

* Personal Mobility Equipment. Description: *“Products to enable personal mobility including equipment for walking, wheelchairs and transfer aids.”*

DBA is curious as to why the ‘specialist’ caveat applied to other categories of equipment is not applied here. It is our opinion that the broadest range of equipment possible should be made available in each domain to best facilitate innovation, customization and cost-effectiveness.

* Vision Equipment. Carve outs that are not NDIS supports: *“Prescription glasses.”*

It is disappointing to see glasses singled out for exclusion in this list. A leading academic in the field of disability studies added the following:

*“For as long as the NDIS has been around, I have been trying to raise awareness about the need to cover the cost of prescription glasses for people with a recognised disability. The need for glasses or refractive error is very common in people with disability, and much higher than other people. Prescription glasses can restore good visual function and can be worn safely. When a person has a refractive error, if glasses are not worn, their access to the world is affected. In people who are deafblind, if their access to vision is compromised, the impact of their dual sensory impairment further increases. In the case of children who are in a visual development period (up to the age of 8 years) not wearing glasses can impact on their vision permanently (a developmental condition known as amblyopia). Vision impairment exacerbated by not wearing glasses can also impact on all areas of a child’s development. The cost of prescription glasses is prohibitive for people and their families. As a clinician I always recommend two pairs for children – glasses are easily lost and broken. Unfortunately, there is no way that families can afford 2 pairs.”*

This statement was further supported by a representative of Deafblind West Australians who added:

*“Completely agree about the addition of prescription glasses. I am happy to pay for the frames, but my prescription needs updating regularly as an inoperable brain tumour grows. I can't understand how this wouldn't be covered.”*

**Supports that are not NDIS Supports:**

* Day-to-day living costs. Description: *“Standard household items (dishwasher, fridge, washing machine, non-modified kitchen utensils and crockery, fire alarms, floor rugs, beanbags, lounges, standard mattresses, and bedding), replacement of appliances including hot water services, solar panels etc.”*

This section as it stands now prevents NDIS funds being used for potentially lifesaving devices such as visual smoke alarms. The caveats put around utensils and mattresses in this rule suggest that non-standard, disability specific options can be funded and this needs to be extended to smoke alarms to reduce confusion.

* *“Business development costs, business skills development costs.”*

Several organisations in the disability sector have spoken of the need to better support small business and microenterprises as part of the employment picture for people with disability. This rule runs contrary to that advice.

* *“Internet services, land line phone, mobile phones, mobile phone accessories, and mobile phone plans and smartphones.*

This list contains several items that in the context of a Deafblind participant do not represent everyday items but essential pieces of accessibility support needed to access the community around them and a host of government services and supports.

For a deafblind person living in a regional area their location, disability, “online-ing” of government services and thin markets of interpreting support mean that their internet and digital devices, and the interpreting services and accessibility features they provide access to, become essential componentry of their citizenry in ways not mirrored in non-disabled users. As regards the exclusion of mobile phones, a representative from Deafblind West Australians adds:

*“This directly conflicts with the communication and information equipment I use as a support. I don't get the NDIS to pay for my phone bill/plan,
but I do expect them to cover the cost of up-to-date tech for my communication needs. It frustrates me that this is listed next to 'gambling' and 'cigarettes. As a teacher, I have used many different AAC devices with my students and they are always hard to navigate, expensive, and lots of the time 'too hard' for the people needing them. A mainstream device is the best option for the user and the supporters.”*

* *“Travel insurance, life insurance, home and contents insurance, car insurance and excess insurance for Novated vehicles (Salary Sacrifice)”*

Deafblind community members have alerted DBA that sometimes home and contents insurance is used for cover on assistive devices such as speech processors. This represents yet another instance of seemingly ‘every day’ expenses arising from disability related needs in a Deafblind context.

* *“Tickets to music, theatre, cinema or sporting events, and general conference fees.”*

Disability conferences that build capacity in families and people living with disability, and in particular those living with rare disease and complex disabilities, should be distinguished from 'general conference fees'. There should also be funding allowed for travel/accommodation to attend these conferences. The impact of rare disease and complex disabilities on the entire family unit is huge. They are isolated in their community from others living with the same rare disease, and from medical and professional experts who understand the disease. Rare disease conferences provide connection to evidence based best practice and a community of shared identity and lived experience. Disability conferences are not a lifestyle choice. They are a critical component in building resilience and capacity in, and improving the mental health and wellbeing of, the entire family unit.

* Not value for money/not effective or beneficial. Carve outs that may be considered NDIS supports for certain participants: *“Therapeutic massage that is directly related to a participant’s disability support needs.”*

It is good to see this acknowledged and that the terminology chosen refers to disability support needs not impairments for which a participant meets access criteria. In theory, this should still allow participants who require physical therapies as part of managing the impact of sensory disabilities to access those services.

**Concluding Remarks:**

DBA is concerned that the structures and processes provided by these lists will further entrench the marginalisation experienced by many Deafblind participants. Deafblindness is not widely understood, not widely represented in academic research and the needs of Deafblind people often do not fit well within administrative frameworks designed to separate a person’s needs into distinct domains of responsibility such as between Commonwealth and State/Territory systems.

We strongly support the calls from other organisations and individuals in the sector for the adoption of a principles-based approach to this issue. In assessing the appropriateness of a specific support to be funded by the NDIS there should be consideration whether or not the support is:

* Reasonable and necessary.
* Related to a person’s disability (as distinct from their impairment/s).
* Take into account what is provided by other government supports.
* Represent value for money.
* Does no harm.