

Submission to Consultation on draft lists of NDIS supports

25 August 2024

Thank you for the opportunity to provide feedback on the draft lists of NDIS Supports.

This implementation approach, including these transitional rules, does not reflect the recommendations of the NDIS Review

The discussion paper for this consultation claims that this transitional supports list (the list) is in response to findings of the NDIS Review¹, specifically that it would increase clarity of what NDIS funds can be spent on. While our experience supporting the mito community is consistent with the findings of the NDIS review that there *'is a lack of clarity and confusion and what the scheme should fund is contested'* (p83), we believe the approach to implementation being taken by the Government, including this list as a part of transitional rules, is not in line with the recommendations of the NDIS Review.

Most relevant to the creation of these transitional rules are these recommendations from the NDIS review:

2.6 National Cabinet should agree to a multilateral schedule to a new Disability Intergovernmental Agreement that replaces the principles for determining the responsibilities of the NDIS and other service systems, including the Applied Principles and Tables of Supports to better clarify respective responsibilities.

3.5 The National Disability Insurance Agency should allow greater flexibility in how participants can spend their budget, with minimal exceptions (recommendation 3.5)

26.2 The National Disability Insurance Agency should ensure existing participants experience a smooth and fair transition to the new participant pathway

These lists will reduce choice and control

The list will persist

As we understand the process, this list will remain in place until all states and territories and the Australian Government agree on a change. This means this transitional list has the potential to persist for a significant amount of time while new ways of working between the states and territories and the Australian Government are established.

The list will fuel existing adversarial decision-making processes with limited right to appeal

Our submission highlights specific examples where the list will not support people impacted by mito to access the disability-related supports they need. There will be many other situations beyond these examples where individual needs do not fit into the list, including where supports have previously been met using NDIS

¹ Available from <https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis>

funding. There will also be situations where the list will be open to interpretation, particularly as the list uses many terms that are not clearly defined.

We understand that the changes to the *NDIS Act 2013* through the *National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No 1) Bill 2024* reduces options for participants to seek review, such as through the Administrative Appeals Tribunal. The existing adversarial decision-making process was recognised in the findings of the NDIS Review.

Therefore, we are concerned that this list will become a new battleground for NDIS participants and NDIS decision-makers. Similar to List A and List B, which were originally intended to guide transition into the NDIS, we believe this list will end up being relied on beyond its original intention.

We are unclear on the consequences of participants and/or plan managers being found to have made the wrong decision about whether a support is an NDIS Support. While the discussion paper states that payments may be delayed or cancelled, we understand that the changes to the *NDIS Act 2013* will mean that participants who are self-managed may be forced to become plan or agency managed. Therefore, this list has the potential to reduce choice and control for these participants.

Other government systems are not equipped to meet needs that will be created by this list

It seems that the justification for many of the items in the list that are identified as not 'NDIS supports' is that these supports should be accessed through other systems (such as health and education).

As we note in our specific examples, access to many of these supports is very limited in other systems. This is particularly the case for health, where allied health services have been reduced and refocused since the introduction of the NDIS. As identified in the NDIS Review, these mainstream services need to be enhanced to reduce reliance on the NDIS. These enhancements must occur before supports are removed from the NDIS. Also, as identified in the NDIS Review, coordination is required across these systems.

This is why the NDIS Review recommended a collaborative and planned implementation approach. We believe that by introducing this list before mainstream supports and coordination have been improved, people with a disability will struggle to identify alternative sources of support and will need to navigate these themselves. Ultimately, this will result in people with a disability missing out on the services they need to live a good life.

There is no guarantee that existing supports will be continued

We are concerned that on the day these transitional rules come into effect, supports that have previously been funded through the NDIS will be questioned, payments will be delayed or cancelled, and participants and plan managers will need to quickly learn about these new rules and how to interpret them.

We suggest that a grandfathering approach is taken to existing supports and reassurance is given to participants that supports that have been previously funded will continue to be funded, including after plan revisions, as this is the intent of these transitional rules.

Survey questions

Feedback on Supports that are 'NDIS supports'

1. Do you think the draft list of NDIS Supports covers the kinds of disability supports you think should be included?

If not, what changes would you suggest?

We have identified several key supports that are missing from the list:

- The inclusion of therapies that aim to maintain or manage a person's functional capacity. These are explicitly included in the Applied Principles and Tables of Support (APTOS)² but are missing from the list. While the draft list includes *Therapeutic Supports*, the description of this states these supports must be aiming to 'to improve participation and independence'. For participants with progressive conditions, maintenance and management are often more appropriate goals, rather than improvement.
- Support for children and families is identified as an NDIS responsibility in the APTOS. For parents with children with mito, some of whom have mito themselves, therapeutic supports are important to help them maintain their caring role. The draft list seems to only include these supports for children at-risk of child protection intervention. These therapeutic supports are distinct from parenting programs, which tend to be disability specific, rather than aiming to sustain family members in their caring role.
- The description of *Assistance With Travel/Transport Arrangements* specifically includes transport to 'school, educational facility, employment, or the community.' Health care needs to be added to this description. Without it, there is a risk that NDIS decision makers will consider transport to health services as not being an NDIS support. This is currently funded through the NDIS plans of many mito community members who are unable to drive due to their reduced functional capacity.
- The description of *Assistance With Travel/Transport Arrangements* states that transport can only be funded 'where the participant cannot travel independently or use public transport due to the impact of their impairment/s on their functional capacity'. This is too high a standard. Many people with reduced functional capacity due to mito could use public transport but may be at high risk of falls. Or they may expend so much of their energy for the day that they are unable to complete other important tasks such as cooking or caring for their children. It is not clear who will make this decision and how this will be made.
- The term 'Specialist products' is used in *Assistive Equipment for Recreation, Assistive Products for Household Tasks* and *Assistive Products for Personal Care And Safety*. This term is not defined and may be interpreted as only including those products that are marketed as disability specific, usually with a premium price. We note that the *Communication And Information Equipment* section does not use this term.

Using 'Specialist products' risks removing the option for non-disability specific products that have

² The Applied Principles and Tables of Support to Determine the Responsibilities of the NDIS and other Service Systems, available from <https://www.dss.gov.au/disability-and-carers-programs-services-government-international-disability-reform-ministerial-council-reports-and-publications/the-applied-principles-and-tables-of-support-to-determine-the-responsibilities-of-the-ndis-and-other-service-systems>

been recommended by a professional to be funded. This would also allow for the funding of mainstream products that can be modified to make them appropriate for a person with the disability. We suggest that the wording is changed to include supports that address disability-specific needs, including non-disability specific products where an allied health professional has recommended them.

- It is not clear how the terms 'specialist care', 'high care needs' and 'high level of skill' in *Community Nursing Care* will be evaluated. These terms should be removed or specific definitions and guidance included.

Feedback on Supports that are not 'NDIS supports'

2. Are there goods or services on the draft exclusion list that you think shouldn't be there? If yes, please list in order of importance

We have found the way the draft lists have been constructed is confusing. To determine if a support is an NDIS Support a reader must check whether it is in the list of NDIS Supports, that it is not part of any carve outs on that list, then check whether it is in the list of not NDIS Supports and not in the list of any carve outs. We recommend simplifying the lists to remove the not NDIS Supports list and have one category based list of what can be funded with specific exclusions as required. This will improve flexibility, reduce risks of different interpretations and improve readability.

Vision related supports

Under *Vision Equipment* there is a specific exclusion for prescription glasses. Prescription glasses for a person with vision impairment caused by mito meet a need beyond the prescription glasses used by many others. For example, one mito community member we consulted requires specially made prisms to be added to their prescription glasses. Without these prisms the person experiences diplopia, which poses a major risk of falls as they cannot perceive steps and changes in gradients. To move around without prisms they need to be accompanied at all times. With this technology, this person can stay in work and move about independently. This person's private health insurance will not fund these prisms or the thinning that ensure that the person does not experience earache and headaches due to the weight of the glasses.

Due to the progressive nature of this person's vision loss, they also require frequent adjustments to their prescription that go beyond the provisions of their private health insurance.

Funding schemes for prescription glasses provided by the states is targeted to people with very low incomes. These schemes are also designed for standard prescription glasses. For example, the WA Spectacles Subsidy Scheme provides a subsidy to a maximum of \$53.85 once every two years. The NSW Spectacles Program is only accessible to those receiving full income support and with almost no assets.

The list of vision supports is also very specific and may not provide the flexibility needed to meet the needs of people with vision impairments. Other low-vision aids include labels, screen readers and large print materials.

Hearing related supports

Similarly to vision related support, the inclusion of *Hearing Equipment* and *Specialised Hearing Services* is positive, but the way these have been described and the reliance on Hearing Australia's services is concerning. The terms 'specialist hearing supports' and 'complex needs' need to be defined. While many people with mito use Hearing Australia's services, many also have needs that go beyond what is provided. This may be because they are ineligible for Hearing Australia's services, they require more urgent assessment, supports or repairs than Hearing Australia can provide, or they require technologies that Hearing Australia does not provide that can only be accessed through the private sector.

The description of these sections needs to ensure that these supports are clearly identified as NDIS supports and that any confusion with NDIS funded supports that Hearing Australia provides (as they are an NDIS provider) is avoided.

Palliative care

We are concerned by the inclusion of ‘palliative care’ in the *Mainstream – Health* list. This risks being interpreted as meaning any support provided to a participant with a life-limiting condition is not an NDIS Support. It is not clear what type of supports will be considered palliative care and who will make these decisions. This is covered more clearly in the APTOS, which confirms that NDIS supports may continue to be provided alongside palliative care provided by health services.

This topic is particularly important to protect choice and control. If the participant has existing therapeutic relationships with NDIS-funded providers, it is inappropriate to push them to access health-funded providers while they are also managing the emotional impact of being given a life-limiting diagnosis.

We suggest that this is changed to be specific to specialist palliative care sub-acute health services. We also suggest that you work with communities that have experience and expertise in palliative care and the NDIS to ensure that these important services can be provided in a coordinated way between both systems.

Support after an acute episode

We are concerned by the inclusion of therapies ‘provided after a recent medical or surgical event’ in the *Mainstream – Health* list. This risks fragmenting care for those that have episodic and progressive conditions such as many types of mito.

For example, people with mitochondrial encephalomyopathy with lactic acidosis and stroke-like episodes (MELAS) are often NDIS participants as their condition progresses due to the impact fatigue, myopathy, and hearing impairment have on their functional capacity. Stroke-like episodes are a common feature of MELAS that lead to the person spending some time in hospital. Many will benefit from therapies on an ongoing basis. Some stroke-like episodes will cause a major decline in the person’s functional capacity, some will not.

We are concerned that the list will lead to people who experience episodic acute events, such as those with MELAS, not being able to access therapies. As these rules will be guiding decisions made by participants, plan managers and agency staff, there needs to be more clarity on who will make the determination of whether a therapy is an NDIS Support or not and what the basis for these decisions will be.

Other feedback on the list

3. Do you have any further feedback or concerns with the draft NDIS support lists?

Feedback on important inclusions

Mito Foundation was pleased to see diabetes related supports included. This has been a valuable support for many in the mito community who do not meet the criteria for subsidised funding through the National Diabetes Support Service (NDSS). Their needs for diabetes technologies is often related to their disability as they may be unable to use a pinprick test due to experiencing neuropathy in their fingertips, fatigue, and/or a loss of coordination.

We are also pleased to see *Exercise Physiology & Personal Well-being Activities* included. These are important ways for people with mito to improve or maintain their functional capacity.

Dietary supplements

The lists could be improved by providing greater clarity on the inclusion of dietary supplement products. Our experience is that this is a type of support that is managed inconsistently today: some participants with mito receive funding and some do not. Dietary supplements are widely recommended for people living with mito. The draft rules include:

- 'nutrition' is included in *Disability-Related Health Supports* section
- 'Alternative or complementary medicine' is excluded in the 'Not value for money/not effective or beneficial' section
- 'Any pharmaceutical'; 'vitamins, sport and athletic supplements' are excluded in the *Mainstream – Health* section

There is no Australian Government funding scheme for these products and many people with disabilities related to mito use these products to improve their health and reduce the impact of their disability. We are concerned that participants who currently have supplements funded as a part of their plans will have these removed, despite the intent of the list being to reflect current practice.

Clarity on evidence-based therapy

The list uses the term 'evidence-based therapy'. We are concerned that when this term is applied to rare conditions such as mito, the lack of formal evidence of effectiveness will be used as a reason to not approve therapies as NDIS supports. The list would be improved by clarifying what quality of evidence is required and who evaluates whether a therapy is evidence-based for a particular participant.

In rare disease, including mito, health professionals who have experience with people with a specific condition are well placed to provide recommendations to the NDIS on specific therapies that may improve or maintain functional capacity.

We welcome the opportunity to work with the National Disability Insurance Agency to develop acceptable evidence-based guidance for therapies for people impacted by mito.

Other opportunities to remove ambiguity

We are also concerned about the ambiguity in the lists, particularly:

- The section *Specialist Positive Behaviour Support* does not define ‘specialist skills’. We suggest this is defined and that the description is changed to ensure that the use of allied health assistants and other non-specialists is included, with monitoring by a professional with specialist skills.
- The section on *Assistance to Access and Maintain Employment or Higher Education* is confusing and needs clarification. The description of what is an NDIS Support includes ‘individual employment support’ but the carve outs include ‘work-specific support related to recruitment processes, work arrangements or the working environment’.
- The section *Assistive Products for Personal Care And Safety* suggests that a portable aspirator (suction machine) might be covered, as without this the participant is not able to maintain their own airway. However this could be considered as a part of a ‘hospital in the home’ service (defined as not an ‘NDIS Support’), despite many health services not providing these machines for use at home .
- The section *Assistive Products for Personal Care And Safety* includes examples of equipment but not consumables. It is not clear whether products such as oral wipes would be considered an NDIS Support.

About our feedback

About mito

Mitochondrial disease (mito) is a debilitating genetic disorder that starves the body's cells of energy. Mito can affect both children and adults and can cause multiple organ dysfunction or failure and potentially death. Due to its genetic basis, mito often affects multiple family members.

There is currently no cure for mito, and very few effective treatments exist. It is estimated that approximately 4,500 Australians live with a diagnosis of mito while one in 200 (more than 120,000) carry a gene change that puts them at risk of developing mito in their lifetime.³

About Mito Foundation

The Mito Foundation provides information and support to hundreds of Australians living with mito, including many people who have disabilities and receive supports through the NDIS linked to their mito-related vision impairment, hearing impairment, mitochondrial myopathy and other physical disabilities.

Mito Foundation is not a provider under the scheme. Our support services use donated funds to help people with mito navigate health, disability, education and other services to improve their lives. Our NDIS Navigator Service was established in 2022 to fill a gap around difficulty with information and access to the NDIS for people with mito. Evaluations of this service have shown that it improved the knowledge and confidence of mito community members in interacting with the NDIS.

In addition to providing support and information to Australians living with mito, Mito Foundation funds essential research into the prevention, diagnosis, treatment and cures of mito, and increases awareness and education about this devastating disease. Mito Foundation was founded in 2009 by families personally impacted by mito along with professionals with a special interest in mito.

Our work is informed by our Mito Community Advisory Panel, and regular engagement with the wider mito community through support services and through research projects. Mito Foundation receives no government funding to participate in NDIS related consultations.

How we developed this feedback

In the limited time available, we have relied on the expertise developed by our NDIS Navigation Service and our wider services team. We invited contributions from the mito community on this topic and received three submissions that have informed this submission.

³ *Preventable burden of mito: Reducing the cost and providing benefits to people with mitochondrial disease and their communities* – April 2024, The Centre for International Economics. CC BY-NC. Available from <https://www.mito.org.au/preventable-impact-of-mito/>

Feedback on the consultation process

Consultation on these transitional rules is essential. The decision to make this consultation only two weeks' long means that the expertise of many individuals and organisations will not be included. We are willing to work with the Department on reforms to the NDIS, including on these transitional rules.

The word limits setup in the online survey did not allow us to use this tool. The number of concerns we had and the detailed considerations would simply not fit into 750 words.

For further information

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