NDIS Proposed New Framework Planning Rules

Submission from Mito Foundation

6 March 2026

Thank you for the opportunity to provide input into this consultation on behalf of Australians living with disabilities caused by mitochondrial disease (mito). Mito is a debilitating genetic disorder that starves the body's cells of energy. Mito can cause vision impairment, hearing impairment, cognitive disabilities, mitochondrial myopathy and other physical disabilities.

This submission contains insights from Mito Foundation's work with the mito community, through our qualitative research program and though consultation activities we conduct with the mito community.

Appendix 1 contains more information about mito related disability and the work of Mito Foundation.

Key risks and recommendations

The new planning framework risks disadvantaging participants with complex, progressive and rare conditions unless specific safeguards are introduced.
Through our *Mito Stories Project*, we have listened to the challenges the mito community experiences accessing disability supports[1]. This group may stand to benefit from planned reforms. However, based on the information shared in this consultation, we are concerned that this group may continue to struggle to access the supports they need. This submission identifies specific concerns and recommendations.

Mito Foundation makes the following recommendations:

1. Develop a staged approach to the implementation of New Framework Plans.
2. Ensure that multiple impairments are recognised for rare and complex disabilities.
3. Design the support needs assessment process to work for people and families with complex, progressive and rare conditions, including mito.
4. Develop and adapt the rules for replacement needs assessments through a pilot approach.
5. Ensure maintenance therapy supports are considered in needs assessment and budgeting processes.
6. Ensure the workforce involved in the new framework planning process has the knowledge and skills they need to work with people with rare, complex and progressive disabilities.
7. Provide participants the opportunity to review their needs assessment and budget.
8. Provide more information about the new budget method.
9. Develop an approach to measure and improve plan flexibility.
10. Improve guidance for participants and their supporters about the changes and the new process.

[1] *Left to figure it out alone: the hidden burden of navigating mito care. The experiences of Australians living with mitochondrial disease in seeking health and disability care* – July 2025, Mito Foundation. CC BY-NC. Available at www.mito.org.au/wp-content/uploads/2025/08/Left-to-figure-it-out-alone-Mito-Stories-Project-Report-1.pdf

> Because of the way they handled my application and the reasons for rejecting it and not giving me the chance to talk to someone and say, "Oh, hey, no, you've got that wrong," that mentally affected me even worse. The way that they do their processes is dehumanising, and it makes you feel worse than you did before you even started them. By the end of that first process, and the first time I got rejected, I wished I'd never heard of the NDIS.
>
> Mito community member

Insufficient information has been provided about new framework plans

This lack of information makes it difficult to respond to this consultation. Mito Foundation has participated in multiple consultation opportunities on this topic and other reforms. This has been through formal submissions[2], through our membership of the NDIA Neurodegenerative Palliative Care and Rare Disease Advisory Group and through our membership of the Rare Disease Disability Network chaired by Rare Voices Australia. Despite these efforts to engage with the reform agenda, we have significant unanswered questions and believe that the current reform plans risk substantial harm. For example, the consultation material leaves critical gaps about:

- how budgets will be calculated.
- how different forms of evidence will be considered and integrated and who will do this.
- how much discretion decision-makers will have.
- processes for corrections and review.
- which groups of participants will be selected to move to the new approach first, beyond the approach of delaying the transition for participants under the age of 16.
- how the process will be made accessible and trauma informed.

This submission highlights key issues and makes recommendations based on the limited information shared in this consultation. We welcome future opportunities to understand further details and to help the NDIA test and validate the new process with participants impacted by rare and complex disabilities such as mito.

[2] Available at www.mito.org.au/driving-change

Detailed Recommendations

1. **Develop a staged approach to the implementation of New Framework Plans**
   Relates to Step 1: Preparing for a support needs assessment
   The current timeframe is clearly at risk. We recommend that a staged approach is co-designed with the disability community that:

   - aims to ensure the new approach works for people with complex, progressive and rare disability
   - ensures participants have some options to delay their transition to new framework plans
   - includes constant validation and review to ensure the new approach is fair and aligns with Australia's human rights obligations.

2. **Ensure that multiple impairments are recognised for rare and complex disabilities**
   Relates to Step 1: Preparing for a support needs assessment
   The transition to new framework plans will lead to existing participants being issued a notice of impairment for the first time. Mito Foundation has been involved in an impairment mapping process for mito, through our membership of the Neurodegenerative Palliative Care and Rare Disease Advisory Group. Our experience suggests that for many people with mito, it will be difficult to determine their impairments. We suggest:

   - The transition to new framework plans includes time to review and revise impairment categories for each participant.
   - The impact that impairment notices will have on new framework plans is explained clearly to participants.
   - The distinction between impairment categories is clarified, particularly the overlapping categories of Intellectual, Cognitive, and Neurological.
   - The new support needs assessment process is only started when a participant has agreed that their impairment categories are accurate.

> "I can understand how difficult it is, because I know, I know three other people with the same diagnosis as me, and yet we are so very different in our stages of the journey… So I understand how difficult it is for anyone to try and put it into a neat little box and tie a bow on it and go "that's what we need". It needs to be individualized."
>
> Mito community member

3. **Design the support needs assessment process to work for people and families with complex, progressive and rare conditions, including mito**
   Relates to Step 2: The support needs assessment
   Specifically, we suggest:

   - Existing specialist pathways, such as those for motor neuron disease and childhood dementia, are retained.
   - Specialist pathways are expanded, based on evidence from existing specialist pathways.
   - The process seeks to understand participant goals and opinions of their support needs.
   - The assessment is designed to understand the whole family, particularly when multiple members live with disability. Because mito is inherited, many families have multiple members with disabilities, even when not all are NDIS participants. For example, will the support needs assessment assume one informal support can support multiple family members?
   - The roles of Assessor and Delegate are combined, such that the person who has interacted with the participant is able to ensure accurate and nuanced information is used as the basis for the budget and any restrictions.
   - The process includes review of advice from professionals, as these often explain the participants' needs and aspects of their underlying condition that may not otherwise be understood in an assessment.
   - The assessment is designed and tested for people with cognitive disabilities that can often be masked during shorter interactions with a person that does not take the time to get to know them, or due to fluctuating capacity.
   - The assessment is designed and tested for people with significant energy limitations, who are risk of fatigue and harm is asked to participate in a long appointment.
   - The process is tested for participants living with complex disabilities, including conditions that are rare and progressive such as mito.

> Some people don't have the energy to do that. I feel really sorry for those that can't advocate for themselves…I'm well enough to be able to do that, and some people can't. And I just think, how do they do that? I feel really sorry [for them].
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> Mito community member

4. **Develop and adapt the rules for replacement needs assessments through a pilot approach**

Relates to Step 2: The support needs assessment

We have found it difficult to provide feedback on this question without understanding more detail about the Support Needs Assessment and the budget process. We recommend that these rules are developed through a diverse pilot stage and that these rules are frequently revised.

We are concerned that the iCAN tool, along with other tools forming part of the new support needs assessment, has not been validated for all groups or for use in this way. We suggest a process of piloting will help to understand which scenarios require a replacement needs assessment.

Some possible scenarios that may require a replacement needs assessment are:

- Participants with a known progressive condition, where projected future needs are not captured in the iCAN
- Participants who can benefit from maintenance therapy supports, where these needs are not well captured in the iCAN
- Participants with rapid onset blindness, where capacity building through early and intensive orientation and mobility training can help them to navigate their environment and adapt to this change in their vision.
- Participants with fluctuating disabilities, where the 'frequency of support' rating may not accurately reflect their changing needs over time.
- Participants who live with energy limitations, for whom the 'level of support' rating in the iCAN may not reflect their limitations.

We welcome the opportunity to explore these scenarios in further detail.

> Because it's degenerative, it's a moving target. So I think you know, if I was the Health Minister, I would want to understand that, that it's not just what Joe Bloggs down the road needs today, we also need to look at what Joe Bloggs needs next month and in six months' time, you know? And I think probably particularly with children in our community, their needs change so rapidly.
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> Mito community member

5. **Ensure maintenance therapy supports are considered in needs assessment and budgeting processes**

   Relates to Step 2: The support needs assessment and Step 3: Building a plan and plan discussion

   Recent NDIS policy acknowledges the important role of maintenance therapy supports, which aims to 'slow the loss of existing skills'[3]. We are concerned that the new framework planning approach will reduce access to maintenance therapy supports because:

   - The iCAN assessment tool focusses on current needs, rather than the potential for maintenance therapy given the participant's progressive condition.
   - It is not clear which other assessment modules would identify whether these supports are appropriate.
   - Many NDIS participants in our community have had their access to these supports reduced, suggesting that their value is not well understood within the NDIS workforce or in policy. This includes reducing frequency of access to once per month, which is often too infrequent to build skills and capacity.

   A lack of maintenance therapy supports can lead to increased future support needs as well as reducing the participants' quality of life. For example, we have previously provided the NDIS Evidence Advisory Committee with information about the role of exercise physiology for people living with mito[4].

[3] *Therapy Supports guideline*, available at www.ndis.gov.au/our-guidelines#therapy

[4] Available at www.mito.org.au/wp-content/uploads/2025/11/2025-Submission-to-the-NDIS-Evidence-Advisory-Committee.pdf

6. **Ensure the workforce involved in the new framework planning process has the knowledge and skills they need to work with people with rare, complex and progressive disabilities**

Relates to Step 2: The support needs assessment and Step 3: Building a plan and plan discussion

This workforce must include NDIS Assessors, Delegates, and decision makers involved in the NDIS new framework planning process. We suggest that training includes:

- evidence-based and participant focussed supports
- guidance on how to assess and meet the needs of participants with progressive conditions, whose symptoms can fluctuate and change unpredictably.
- an understanding of energy limiting conditions, including disabling fatigue.

The approach to workforce development should be shared in a transparent and open way. The approach should include collaborations with non-government organisations who can provide expert input, helping the workforce understand complex, progressive and rare disability.

A new approach is needed to workforce development. The experiences of the mito community highlights the importance of specialist knowledge

- Several of our community members have been impacted by a lack of understanding of vision loss and the way this is measured, leading to participants being excluded from the scheme despite meeting criteria for blindness.
- Psychosocial support needs being overlooked as NDIS decision makers and delegates are not aware that this is a common disability associated with mito
- Participants being incorrectly told their diagnosis is incorrect because their diagnosis did not impact people of their gender.

> ...every time I seem to have a question, which is, maybe once every couple of months, the NDIS person that I'm allocated has moved on. So you're always getting someone new who doesn't know about your condition. So whenever, if ever, you put a review, or if the NDIS is reviewing your case at the end of the year, or something, you have to go through the whole thing again. And you know what it's like. It's so hard to explain to someone who doesn't know what mitochondrial disease is. So, for them to actually get it or get an understanding of it, that's annoying and it's time consuming and stressful.
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> Mito community member

7. **Provide participants the opportunity to review their needs assessment and budget**

   Relates to Step 2: The support needs assessment and Step 3: Building a plan and plan discussion

   Participants and their nominees must be given a reasonable time period to review the Support Needs Assessment report. For example, this would allow them to identify:

   - Factual errors.
   - Situations where the combination of multiple assessment tools has led to the participant's needs not being reflected in the report.

   Participants must also be given a reasonable time period to review a draft budget, along with the basis for the budget (for example, raw iCAN scores, loadings and weightings).

8. **Provide more information about the new budget method**

   Relates to Step 3: Building a plan and plan discussion

   With implementation only months away, we are concerned that no information has been provided on how the Support Needs Assessment Report will be used to determine a budget for the participant. We are not aware of any planned consultation on this topic.

   This is deeply concerning, particularly in combination with concerns about the pace of the roll out and the limited options for review after a budget is developed.

   To ensure the budget method works for the mito community, we suggest:

   - Informal supports are not assumed to be available for any participant over the age of 16. These informal supports are at significant risk of carer burnout and many share with us that they want to be able to return to their role as spouses, friends, children and parents. It is unsafe for the budget method to make assumptions about capacity, availability and sustainability. This is particularly the case for families with multiple members living with disability, which is often the case with mito and other genetic conditions.
   - Explanations are provided about how the budget rules have been used to develop a participant's budget
   - The process does not assume that NDIS assessment outputs are of higher value or given more weighting than assessments conducted by allied health professionals.
   - Budget rules must account for progressive conditions where needs are expected to increase during the plan period.

9. **Develop an approach to measure and improve plan flexibility**

Relates to Step 3: Building a plan and plan discussion

One of the stated goals of New Framework Plans is to 'result in simpler plans that are more flexible'. This goal is at significant risk due to the combination of:

- The broad set of supports included in the list of stated supports under New Framework Plans
- The new requirements for receiving a service or buying supports that will be part of New Framework Plans
- Increasing rules that are driving more participants to be NDIS managed
- The recent introduction of funding periods, where the default is being often set to 3 months.

This approach needs to be revisited to ensure these reforms achieve the goals of the NDIS review. We suggest that the agency adopt goals for plan flexibility and track progress against these goals. This will provide an incentive across the agency to increase flexibility. For example, metrics could be: the proportion of plans with no funding periods shorter than 12 months; the proportion of funds provided as flexible (rather than stated).

The Neurodegenerative, Palliative Care and Rare Disease Advisory Group has made a submission to the agency (*NPRAG position paper on funding periods*) proposing that the default funding period for all participants with a progressive condition be at least 12 months. This should also be considered to achieve the stated goal of more flexible plans. We have not received a response to this submission. Participants living with mito report that even when specifically requesting 6- or 12-month funding periods due to the progressive nature of their condition, these are refused.

> Things like psychology, you need to get, you need to be able to make your own decisions about who you want to see, because you need to connect with your psychologist. It's no point seeing someone who you don't connect with. Things like that. I just wanted that choice myself.
>
> Mito community member

10. **Improve guidance for participants and their supporters about the changes and the new process**

    Relates to Step 1: Preparing for a support needs assessment, Step 2: The support needs assessment, Step 3: Building a plan and plan discussion and Step 4: Starting to use a plan

    A person-centred approach to change management must:

    - Provide clarity to individual participants about when their lives will be impacted by this change, in a manner that is reassuring and welcomes questions.
    - Provided a range of accessible fact sheets that support participants to prepare for the change. Specifically, these topics require dedicated resources:
        - clear explanation of impairment notices
        - guidance on how to prepare for assessments
        - transparency about how budgets are calculated
    - Equip local area coordinators and other NDIS contacts to provide tailored advice to participants.

For further information

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Appendix 1: About our feedback

About mito

Mitochondrial disease (mito) is a debilitating genetic disorder that starves the body's cells of energy. Due to its genetic basis, mito can affect 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[5].

Mitochondrial disease can affect both children and adults, often causing multiple organ dysfunction or failure and, in severe cases, death. For the most serious forms presenting in childhood, the mortality rate can be as high as 50% per year[6].

Mito can cause many different disabilities, including sensory impairments (e.g. vision loss, hearing loss), physical impairments (e.g. muscle weakness, ataxia, pain), and cognitive impairments (e.g. developmental delay, memory and attention difficulties, seizures). Often the combination of multiple disabilities results in a substantial impact on the person's everyday life.

For some people with mito, these disabilities develop over a longer period of time as the condition progresses. For many, the progression of their disease brings sudden onset of symptoms and impacts and an immediate need for urgent support.

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[5] *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/

[6] Noorda G, Hermans-Peters M, Smeitink J, van Achterberg T, Kemps H, Goverde W, Schoonhoven L. *Mitochondrial disease: needs and problems of children, their parents and family. A systematic review and pilot study into the need for information of parents during the diagnostic phase*. J Inherit Metab Dis. 2007 Jun;30(3):333-40. doi: 10.1007/s10545-007-0426-0. Epub 2007 May 11. PMID: 17508266; PMCID: PMC2794030.

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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.

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 consultations.