

9 September 2021

Re Mito Foundation's response to NDIA Consultation Paper: *An Ordinary Life at Home*

The Mito Foundation welcomes the opportunity to contribute to the development of the NDIA's new Home and Living policy. This submission is provided with the aim of informing the way NDIS participants with mitochondrial disease (mito) are supported to pursue their home and living goals.

Background

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. This assistance is particularly valued by people with mito as they are often living with significant fatigue.

Key issues

The consultation paper highlights many of the challenges people with mito experience. Addressing these issues will contribute to people with mito having true choice and control over where they live, with whom they live and the supports they use at home.

Some of these are consistent with the issues identified in section 3.4 of the consultation paper:

- *Changes in day to day life need a quicker response:* Many people with mito have needs for support that change, including gradually increasing needs and more significant changes caused by acute health episodes.
- *Not enough support options or appropriate housing:* Many people with mito are unable to work or work enough hours to cover daily living expenses. Social and public housing is often unavailable or subject to long waiting lists. The private rental market offers insecure tenancies. Many people with mito find it difficult to obtain

disability support pension and other income support and this income is often insufficient to cover day to day living costs.

- *Lack of community, capital and capacity building supports in plans:* Maintaining and improving community connections is a goal for many people with mito. Too often our experience is that NDIS funding for transport and support worker time is used up by other goals such as attending necessary medical and allied health services.

Other key issues experienced by people with mito are:

- *Home modifications on private rental properties* – When a person with mito rents their own home and requires home modifications, these are difficult to get approved.
- *Long approval times for home modifications* - The need for comprehensive assessments and multiple approvals can mean up to a year spent waiting for modifications. For one child with mito who needed a shower entry levelled to allow his parents to safely support him to have a shower, approval has taken over 12 months.
- *Housing needs that are not recognised by mainstream housing providers and/or the NDIS* - Due to difficulties in regulating their own temperature some people with mito need air conditioning in areas where it would not normally be required. Children with mito also need safe shaded outdoor play areas when they cannot play in the sun. Providers of social and affordable housing are often not able to meet these needs and modifications are often excluded from NDIS plans.
- *Overreliance on parental responsibility for children with very high needs* – young children with mito often require support from two people for 24 hours a day in their home. Families of participants have found that even with appropriate allied health and medical reports to explain these support needs, NDIS plans often exclude appropriate supports because the participant is a child. Having parents provide this intense level of care constantly goes beyond parental responsibility and has a significant impact on the health of parents, siblings and the NDIS participant.
- *Lack of support for older parents to secure long term housing for their adult child*– These parents can find themselves providing housing and 24/7 support for their child right up until they enter residential aged care or pass away. These families need to be identified and actively engaged to identify options that support the independence of their child and address the concerns of the parents as they age.

Amanda's story

Amanda's story illustrates some of the challenges faced by adults with mito.

Amanda* is 61 years old and lives with mitochondrial myopathy, profound hearing loss, moderate visual impairment, and severe pain. Amanda has been an NDIS participant since its rollout in her state. In 2019, Amanda moved to a different state to be closer to family.

Amanda was approved for specialist disability accommodation as a part of this move. While she was awaiting a Specialist Disability Accommodation (SDA) placement, Amanda moved into a residential aged care facility. Amanda understood that this would be for 3-4 months.

After 12 months in residential aged care, Amanda moved to her new home with a local SDA provider who had told Amanda they had a suitable option for her, particular to support her goal to maintain her independence.

After moving in Amanda discovered that this accommodation did not meet her needs. The policies and practices in the house were designed for the needs of people with an intellectual disability. For example, no visitors were permitted in the house as one of the residents became agitated around new people. This meant that Amanda's son, who lived nearby, could not visit her at home. Amanda was also 'not allowed' to do things for herself, including managing her medication, attending medical appointments, having a mobile phone and closing the door to her own bedroom.

Amanda attempted to find a solution with the SDA provider for over a year, but was told repeatedly that they had no other options for her. The provider agreed to make changes, but these were not followed through by staff working in Amanda's home.

Amanda is now supported to live in a small unit with access to support for personal care, cleaning and food preparation. This means Amanda has some privacy, is able to maintain relationships with her family, build connections in her new community and her mood has improved. Amanda has control over her life again.

** Name has been changed to protect Amanda's privacy*

The proposed policy changes in the *An Ordinary Life at Home* consultation paper would assist in supporting Amanda. Particularly:

- Changing the conversation to involve Amanda in talking about who she wanted to live with and where, rather than what type of housing she was approved for.
- Having Amanda's local area coordinator (LAC) and NDIS planner be more informed about available housing options.
- Making processes shorter and more practical when a short term change is needed

Recommendations

Mito Foundation supports many of the recommendations in the *An Ordinary Life at Home* consultation paper. This includes the proposal for the expansion of Independent Living Options and increased flexibility in how budgets can be used, which will support increased choice and control.

The consultation paper describes an intent for the NDIA to work with providers to improve SDA options including reducing the size of group homes and increasing the independence between providers of different types of support. We support these proposals.

The focus on supporting participants to explore and design options and transition to appropriate home and living solutions is welcomed. This will particularly benefit young adults with mito as they explore options to move out of their family homes.

People with mito are at risk of being moved to residential aged care when there are no other options that can be explored within their plan funding. Addressing these issues will contribute to the success of the *Younger People in Residential Aged Care - Action Plan*¹.

1. Work with other agencies to improve housing options and reduce the number of people with disabilities living in poverty

Mito Foundation acknowledges that some of the challenges above lie outside the legislated and agreed responsibilities of the NDIS. We believe it is the responsibility of the NDIS to share the findings of this consultation with other Commonwealth government agencies, particularly the Department of Social Services.

In our experience, current arrangements and processes are frequently not in line with the principle 6 in the *Council of Australian Governments Applied Principles and tables of services*²:

'The interactions of people with disability with the NDIS and other service systems should be as seamless as possible, where integrated planning and coordinated supports, referrals and transitions are promoted, supported by a "no wrong door" approach'.

Collaborations with the State and Territory governments that build on the National Housing and Homelessness Agreement, are an opportunity to highlight the unmet needs for public, social and affordable housing for people with a disability.

¹ www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-younger-people-with-disability-in-residential-aged-care-initiative/younger-people-in-residential-aged-care-action-plan

² <https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf>

Income support for people with disabilities is closely related to their housing options. Mito Foundation would welcome collaboration between the NDIS and the Department of Social Services to improve targeting of the disability support pension and collaborate on other initiatives to reduce the number of people living with a disability living in poverty.

2. Improve NDIA's understanding of needs of people with rare disabilities, including mitochondrial disease

The mito community constantly seeks support from the Mito Foundation to explain their disabilities to NDIS LACs and planners. This often involves significant fees for allied health assessments and additional work from medical specialists to explain the support needs linked to mitochondrial myopathy and other disabilities. Even when this preparation has been extensive, plans are approved that do not include appropriate supports that have been recommended by health professionals.

There are significant opportunities for NDIA and partner organisations to improve their understanding of rare conditions. Mito Foundation is happy to work with NDIA and partner organisations to improve this.

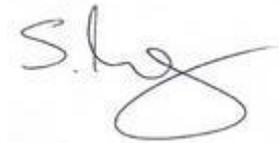
3. Ensure that funding budgets are sufficient to allow people to live an ordinary life at home

The *An Ordinary Life at Home* consultation paper includes many references to participants making decisions on how to use their 'NDIS budgets'. While Mito Foundation understands that NDIS plans will always have a funding value attached, we are concerned that the emphasis on consistent 'budgets' is indicating a narrowing of options available to participants to only those that are possible within NDIS funding that may be insufficient. Mito Foundation encourages the NDIS to provide adequate funds for participants' reasonable and necessary home and living supports rather than setting consistent budgets that do not reflect the needs and contexts of individual participants.

Many people with mito are already clear regarding their home and support goals. For many adults with mito they want to remain in their own homes with support for both their disability and health needs provided in an integrated way. For many children with mito, their goals are to remain in their family home with support provided by their parents combined with allied health professionals and support workers when their needs exceed parental responsibility. Their goals can only be met with sufficient plan funding.

Thank you for the opportunity to provide input to this consultation. Mito Foundation is more than willing to work with NDIA on this and future reforms. Further information can be provided by contacting our Policy and Advocacy Manager Clare Stuart on 0410 685 181 or clare.stuart@mito.org.au.

Yours faithfully,



Sean Murray
Chief Executive Officer