

Response to the NDIS Act Review and Participant Service Guarantee (Tune Review)

**Australian Government:
Department of Social Services**

**Submitted by:
MND Australia**

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Background

MND Australia is the national voice for motor neurone disease (MND). MND Australia and its members, the State MND Associations, form the only national network focused on improving the lives of all Australians living with motor neurone disease (MND).

For over 35 years this national network has helped increase understanding of the disease and advocate for improvements in its treatment and care to ensure people living with MND have the best quality-of-life possible. Over the last 32 years this network, through its research arm MND Research Australia, has invested \$32 million in world-class research in the search for effective treatments.

The six state MND associations provide direct support and services to people living with MND in all states and territories.

ABOUT MND

MND is the name given to a group of neurological diseases in which motor neurons, the nerve cells that control the movement of voluntary muscles, progressively weaken and die. With no nerves to activate them, the muscles of movement, speech, swallowing and breathing gradually weaken and waste, and paralysis ensues.

MND affects each person differently with respect to initial symptoms, rate and pattern of progression, and survival time.

Average life expectancy is 2 to 3 years from diagnosis.

There is no known cause for MND (except in a very small number of genetic cases) and no effective treatments. There are no remissions and progression of MND is usually rapid and relentless creating high levels of disability and a consequent need for a wide range of progressively changing supports.

THE CHALLENGES

The social and emotional impact of MND is amplified by its complex nature, the speed of its progression and the spiraling series of losses that pose:

1. huge problems of adjustment for people who have MND;
2. an escalating and stressful burden on carers and families
3. a challenge to health professionals, disability services, community care, and aged care providers involved in meeting the variable, progressing and complex care needs, particularly in regional, rural and remote areas; and
4. the need for a coordinated response that addresses the person's disability

Timely early intervention and access to expert multidisciplinary care, assistive technology (aids and equipment), specialist planning and assessment and coordination of support, including a proactive framework for decision-making, play vital roles in maintaining quality of life and independence. It also helps people to plan ahead to prevent crisis and avoidable hospital/residential aged care admissions.

Although early intervention will not slow down the disease process in MND, it will strengthen the informal supports available to the person, including supporting the primary carer to maintain the caring role and their own health and wellbeing.



Improving the NDIS experience for people living with motor neurone disease (MND)

Submission

MND Australia recognises that the NDIS is a once in a lifetime opportunity to transform the lives of people living with disability. Over the last 10 years we have worked in partnership with our members, the six state based MND Associations, and the MND community at the grassroots, local, state and federal levels to influence the development of a scheme that meets the needs of people living with motor neurone disease (MND). At the same time we have worked proactively with the NDIA to provide information, support and cost effective solutions.

Today many NDIS participants living with MND have plans that are having positive, life-changing impacts; many others, however, continue to experience a protracted planning process and struggle to receive plans that take their progressing and complex needs into account.

MND Associations across Australia have worked to support people with MND eligible for the NDIS since its inception, offering pre-planning support and information and, where requested attendance at planning meetings. For the past six years MND Advisors have witnessed the broad spectrum of quality of NDIA Plans.

The NDIA and MND Associations have worked together at a national level to develop an MND specific Practice Guide to support planners to take into account the progressing needs of people living with MND when developing plans. The Planning process has consequently improved dramatically over the last 12 months. However, inconsistencies continue with differing plan processes and plan quality being experienced in each state or even in each region within each state.

There are approximately 2,000 people living with MND in Australia and, in most states and territories, 80 to 100% of all people with MND become members of an MND Association. Around 40% of people are under the age of 65 when diagnosed and therefore entitled to access the NDIS. People with MND turn to the Associations for expert advice and education which places MND Associations in an ideal position to be the specialist providers of support coordination, assistive technology (AT) rental and pre planning support for this small but complex NDIS cohort.

A 2015 Deloitte Access Economics Report commissioned by MND Australia reveals that the per person cost of MND in 2015 was \$1.1 million, dwarfing the cost of many other chronic health conditions¹. The report states that aids and equipment comprise one of the highest costs at \$31,598 per person per annum. The report confirmed the MND Association equipment loan service as a cost effective model in providing equipment to maintain independence and communication.

In this submission MND Australia will address the key issues under review as they relate to people living with MND.

¹ Deloitte Access Economics 2015, [Economic analysis of motor neurone disease in Australia](#), report for Motor Neurone Disease Australia, Deloitte Access Economics, Canberra, November



What could a participant service guarantee look like?

Possible principles for NDIA service standards:

All the principles outlined are important for people living with MND in particular those principles that relate to a timely, engaged and expert approach.

MND is a complex and progressing life limiting neurological condition with an average life expectancy of just three to five years. Time, as well as an understanding of the complex needs of people with a diagnosis of MND is therefore of the essence in initiating effective services and supports as rapid paralysis and increasing disability are hallmarks of MND.

Many of the issues experienced to date have been related to the complexity of the scheme and delays with respect to planning and the review process. Making the NDIS process easier to understand and use would enable decisions about access, planning and reviews to happen in a more timely manner.

Effective NDIA engagement with people living with MND and their families is critical to a person centered approach.

An expert approach is vital for people living with complex conditions such as MND to ensure the best participant experience and effective use of public funds. However, most planners are disability specialists and have little experience nor understanding of progressive neurological conditions such as MND and the wide ranging disabilities that these conditions create.

People with a diagnosis of MND should be designated to specialist planners, who are well informed and experienced in assessment and understanding of the current and changing needs of a person with a progressive neurological condition.

MND Australia has always advocated that specialist disease organisations are best placed to provide planning for people with complex and progressing conditions such as MND.

Connections across disability and health systems as well as specialist providers are imperative for people living with MND as the wide ranging and complex symptoms of MND require support from many different providers. Evidence confirms that a coordinated, multi/interdisciplinary team approach² improves the lives of people living with MND and that non-invasive ventilation improves survival by 13 months on average³.

Whether the NDIA is currently fulfilling the principles as outlined is debatable at this time:

² Martin et al, 2017, "The benefit of evolving multidisciplinary care in ALS: a diagnostic cohort survival comparison", *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration* 18(7-8)

³ Berlowitz et al, 2016 –Identifying who will benefit from non-invasive ventilation in amyotrophic lateral sclerosis/motor neurone disease in a clinical cohort, *J Neurol Neurosurg Psychiatry*, 2016 Mar; 87(3): 280-6.



Timely – falling short in many pathway processes– some access decisions still take three to 12 weeks; planning meetings, review decisions and rectifying of simple mistakes often takes too long.

Expert – many people with MND are still not receiving plans that take their progressing symptoms into account. This is mainly due to inconsistencies in the planners' level of expertise and understanding of MND.

Decisions made on merit - this is open to interpretation by NDIA staff resulting in inconsistent outcomes for participants. The advice of specialist allied health staff making assessments is often ignored resulting in delays and unnecessary stress for participants.

Connected - When a plan is changed or reviewed prior to its end date, there is no system in place to communicate those changes to all the linked providers making the claiming process administratively intensive.

Accessible – relates to the NDIS being accessible to all people with a disability and should therefore also include those who acquire a non-age related disability over 65 years of age. For the 60% of people diagnosed with MND when aged 65 or older, access to disability services and support is severely limited.

As highlighted throughout this submission inconsistency is a common issue and therefore **consistency** should be included as a key principle in a Participant Service Guarantee.

The service standard related to the **expert** principle should include reference to the requirement for staff to undertake training and to follow practice guides developed by the NDIS with expert external advice. These are not always used by planners to guide and inform plan development.

Measuring how many plans result in reviews or requests for increased funding should act as one measure of how well the NDIA has delivered on each of the principles. Surveying participants and service providers could also be considered.

The NDIS participant experience

Building an NDIS Participant Service Guarantee

Getting started: Eligibility and application

One of the significant challenges faced by NDIS participants with MND in the access process is the sheer volume of information required which can be overwhelming. The need to identify an allied health or medical professional who is experienced in completing access requests is also a hindrance. When the Access request part A is not completed in the way required by the NDIA the access request is often rejected.

If the NDIA contacted the medical or allied health practitioner proactively to request more information rather than simply rejecting the access request then this would make access easier and quicker. It would also identify the organisations that may



need more training and/or up skilling on the access process and make access quicker and easier in the future.

The current requirement for the NDIA to make a decision on an access request within 21 days is too long for most people with MND. Ideally it should take no more than five working days to make an access decision for people with progressing neurological conditions.

The early intervention requirements stipulated in the NDIS Act imply that in certain situations a diagnosis, including neurological conditions, that results in permanent disability should be sufficient to access the NDIS. In reality people are frequently refused access if they can't demonstrate functional limitations at the time of the application. To make it quicker and easier to access the NDIS people diagnosed with a condition that is likely to progress rapidly such as MND should have automatic eligibility for the scheme and not have to demonstrate functional impairment.

It would be helpful if the NDIS provided a direct contact to the Access team rather than the generic 1800 number or a fast track to Access team specialist staff member as an option via the 1800 number.

With respect to transparency some decisions are being made with little or no regard to the future needs of participants. If access is denied then the person should be given the specific reasons. A generic letter is not acceptable. While some disabilities are static in their needs the future need of people with progressive conditions and disabilities are often not accounted despite the clear recommendations in the MND Practice Guide for Planners.

Planning processes 1: Creating, your plan

The overarching focus on developing a plan structured around the person's goals and aspirations is challenging for people with a limited life expectancy. The planning process for a person with a complex and progressing condition like MND requires specialist support, empathy and expert knowledge of the condition.

Some of the significant challenges in the planning process faced by people living with MND include the time it takes and planners' lack of knowledge. Experience has shown that when NDIS planners lack knowledge of MND, poor plans and multiple plan reviews are generally the outcomes, with some proceeding to judicial review.

Since the introduction of the NDIS MND Associations covering each jurisdiction have worked to support people living with MND and their carers throughout the planning process. MND Association Advisors work to provide pre-planning support and information and attend planning meetings when invited to do so.

At the national level MND Australia has worked with the NDIA to effect systemic change to ensure people living with MND have access to planners with some experience of MND or progressive neurological conditions whenever possible.

Although overall the planning process is improving for people living with MND inconsistencies and challenges continue. MND Association engagement with the NDIA nationally over many years has established that people with MND should always be referred to a planner not an LAC for plan development. In most cases this



happens and this has generally had a positive impact and minimised the need for multiple plan reviews. However, in some jurisdictions access to a planner continues to be hit and miss.

Despite a direct referral to a planner, in most instances, the large turnover of NDIA staff, including planners, impacts on building experience and expertise. The NDIA has committed to identifying key lead planners in each region, but this remains sporadic.

This lack of expertise and experience with people who have a progressing disability and a limited life expectancy leads to significant challenges in accessing assistive technology (AT) in a timely manner. Funding for AT provision in a plan (rental or purchased) varies considerably depending on the planner.

The planning process should take no more than 30 working days for people diagnosed with a life limiting and progressing neurological condition. As previously stated it should take no more than five working days to make an access decision. We would then recommend that there should be a maximum of 20 working days from access approval to the planning meeting and plan build should take no more than five working days (assuming all the information requested is available at the time of the planning meeting).

For people living with MND with a limited life expectancy the sooner their plan can be developed, approved and enacted the better. To make this process as quick as possible the NDIA should ensure that the process outlined in the MND Practice Guide is followed. In addition funding the pre-planning work undertaken by specialist support organisations to prepare people for their planning meeting should be formally recognised and appropriately funded.

The information provided by the NDIA to clients mostly consists of links to websites and LAC services that are very generic and not appropriate for people with MND. Pre-planning is vital for people living with complex and progressing conditions. The MND Advisor is best placed to provide pre-planning support as expert knowledge about the disease progression is critical to developing a good plan in a timely manner.

Responsiveness and transparency relating to decisions made regarding participants plans could definitely be improved. Funding supports discussed at the meeting are bundled up into gross amounts with little description about what has been included. This is done to “increase flexibility”, but is not helpful in enabling a client to understand what aspects of their requests are included in the plan. Having said this, flexibility is important and a balance needs to be struck.

Another issue that keeps emerging relates to life expectancy. In our discussions with the NDIA we have been reassured that the planner should not take life expectancy into account when assessing a person for AT to address their reasonable and necessary needs at that time. However, the perception remains that life expectancy is limiting the allocation of funding to purchase customised equipment items. This is disputed by some NDIS staff but many clients are adamant their planner advised them that this was the case.



More recently MND WA has reported that as the NDIS rolls out in Western Australia planners are requesting a letter from a medical specialist to determine prognosis before a motorised wheelchair, or similar, can be included in the plan to ensure that it is the 'most effective option to meet long term needs'.

Planning processes 2: Using and reviewing plans

There are a number of significant challenges faced by NDIS participants living with MND in using the supports in their plan. In some jurisdictions it is hard to engage providers, particularly allied health professionals, to deliver supports to people with MND.

Neither planned nor unplanned reviews are timely enough. A planned review should take place well in advance of the current plan expiry and an unplanned review, often due to a crisis or rapid deterioration, should be prioritised. In addition the NDIA are not accepting unscheduled plan review requests from anyone other than the participant. The NDIA needs to allow a representative to request reviews (with participant approval).

From a service provider's perspective, claiming needs to be less administratively difficult and NDIA communication should be proactive when a plan is changed. Continuation of services (where a participant desires it) should also be allowed without burdensome paperwork requirements. Introducing these changes would improve and streamline the review process.

There is often a 'use it or lose it' view of funds within a plan which does not recognise that a person may be using funds responsibly based on changing need or accessibility of services. They should, therefore, not experience a reduction of funding unless it is clearly identified that a need no longer exists.

Appealing a decision by the NDIA

One of the significant challenges faced by NDIS participants when seeking a review of an NDIA decision is not being able to discuss decisions made with an informed NDIA representative. One point of contact as suggested in the discussion paper would be a positive development.

In addition internal and external reviews trigger a new set of plan dates and this is not always communicated to the client and /or Support Coordinator.

The NDIA could improve the review process by streamlining the consent process to enable participants to nominate a person (which could include a support coordinator) to be main point of contact for review issues.

The legislative framework

Recognising and appropriately funding pre-planning provided by specialist support organisations within the NDIS Act and the Rules would improve the way participants and providers interact with the Scheme. It would also streamline the planning process saving time and money in the longer term.



The access request process may also be improved if there were greater understanding of the legislation around early intervention (particularly with newly diagnosed progressive neurological disorders).

The participant planning and assessment process could be improved through better understanding of complex needs of people with progressive neurological conditions. This includes internal training in how to use the MND Practice Guide and the introduction of specialist planners for people with progressing and life limiting conditions.

The NDIS Act outlines the meaning of the term 'reasonable and necessary' in determining what supports will be funded by the NDIS. The service guarantee needs to include clear guidance on interpreting reasonable and necessary support for people with life limiting conditions. Decisions regarding access to AT to support comfort and independence should not be based on life expectancy but on the advice of specialist allied health professionals and the needs and wishes of the participant.

Plan amendments

One of the significant challenges faced by NDIS participants in changing their plan is having to re-establish previous arrangements that were working effectively. Plan amendments as suggested in the discussion paper would be a positive development for people living with MND.

Quicker and easier ways to make changes to AT quoting and the home modification process is important for people living with MND.

An allowance within a plan for unanticipated changes would address changes in circumstances that require urgent extra support. For example if a participant chooses to rely solely on informal supports for personal care, an allowance could still be made in plans for a months' worth of funded personal care as a back-up option in case their carer becomes unwell. This would buy time to determine if the need was short term or if a plan review was required.

The process for making changes to plans could also be improved if the NDIA communicated the change of details to everyone with a service booking as part of the original plan. This would solve many administrative problems for providers when claiming.

MND Australia thanks the Australian Government for the opportunity to respond to this Review of the NDIS Act and Participant Service Guarantee. We would be pleased to provide further information if required.

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