

Response to Productivity Commission Issues Paper

NATIONAL DISABILITY INSURANCE SCHEME (NDIS) COSTS

Submitted online

MND Australia

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Executive Summary

MND Australia believes that the National Disability Insurance Scheme (NDIS) will transform the lives of people living with MND and has promoted and supported the Scheme since its inception.

To date some NDIS participants have received plans that have had positive, life-changing impacts on their lives, however, many others have received insufficient plans that will adversely affect their quality of life and place some at risk of avoidable hospitalization.

To ensure the best outcomes for people with MND and to save costs under the NDIS, MND Australia recommends:

- People with rapidly progressing conditions such as MND recognised as early entrants to the Scheme
- Improved pre-planning support for people with MND
- NDIS planning sessions that recognise the unique needs of people with MND
- Appointing MND Associations as planners for people with MND
- Application of the ***Practice Guide for Motor Neurone Disease*** by all planners
- A process for regular plan amendments rather than full plan reviews for people with rapidly progressive disease
- Mandatory inclusion of Coordination of Support in all NDIS plans for people living with MND
- Include option for the MND Associations equipment 'bundle' as part of a person's support plan to enable fast track access
- All LAC's and NDIA staff involved with people diagnosed with MND to undergo funded training provided by the MND association ; and
- The needs of people with a progressive neurodegenerative disease addressed in this Review of NDIS Costs – see Neurological Alliance Australia Position Statement¹.

¹ <https://www.mndaust.asn.au/Documents/Policies-and-position-statements/Neurological-Alliance-Australia-position-paper-on.aspx>

1 Introduction

During the roll out of the NDIS the MND Associations in NSW and Victoria have reported increasing issues related to the planning process, the implementation of plans and coordination of supports. Our recent engagement with the NDIA has led to the development of a ***Practice Guide for Motor Neurone Disease*** to assist planners to develop an initial plan that will address the progressive nature of MND and minimize the need for repeated assessments. This practice guide should shorten the planning discussion and process while retaining participant control over their plan.

We are hopeful that this planning guide will be taken up and applied nationally to improve outcomes for people living with MND.

MND POPULATION ELIGIBLE FOR THE NDIS

It is estimated that there are currently 2,000 people living with MND and around 50% of these people were diagnosed when under the age of 65.

The crucial issue is to recognise that MND is a rapidly progressive condition resulting in complex and changing needs and, ultimately, death. MND therefore requires a rapid and responsive approach from diagnosis onwards.

MND does not fit the NDIS model of capacity building due to:

- Rapidly progressing changing disability needs created by the disease
- Complex needs related to:
 - Increasing limb weakness leading to inability to maintain independence without timely access to assistive technology
 - Increasing difficulties with speech with some people being nonverbal leading to inability to communicate needs without appropriate assistive technology
 - Increasing disability leading to inability to maintain personal care and consequent need for increasing levels of personal care and support
- Increasing carer burden
- The terminal nature of MND

Coordination of supports is required throughout the disease trajectory due to complex and progressing needs, the need for early responses to changing and escalating needs, and to ensure a person's plan is enacted.

Based on over 35 years of experience MND Associations are best placed to assist people with pre-planning and the planning process, to provide coordination of supports and specialist training, and to delivery assistive technology on a needs based rental basis. MND Association engagement in these services provides efficient and effective application of NDIA funds, better outcomes for clients, a responsive service model that recognizes and adapts to changes and increasing disability, and ensures effective delivery of assistive technology to maintain independence, support community engagement and promote safety for paid and unpaid carers.



Background

MND Australia is the national peak advocate for motor neurone disease (MND). Together with the state MND associations and our research arm, the MND Research Institute of Australia (MNDRIA) we advance, promote and influence MND care and research with a vision to achieving a world without MND. The six state MND associations provide direct support 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 neurones, 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), no effective treatments and no cure. 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
4. the need for a coordinated response that addresses the person's disability; and
5. significant problems for service delivery models that are not experienced in rapidly progressive and degenerative disabilities

Timely early intervention and access to expert multidisciplinary care, assistive technology, 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. Early intervention 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 strengthens the informal supports available to the person, including supporting the primary carer to maintain the caring role and their own health and wellbeing.

People living with MND face many challenges but accessing the right care, in the right place, at the right time should not be one of them. The complex and progressing nature of MND requires a coordinated interdisciplinary approach

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encompassing health (GPs, neurology, respiratory, gastroenterology, neuropsychology, nursing, palliative care and allied health), disability, community, aged, respite and carer support services.

A recent Deloitte Access Economics Report reveals that in Australia the per person cost of MND in 2015 was \$1.1 million, dwarfing the cost of many other chronic health conditions. The report, commissioned by MND Australia, is the first Australian study of the economic impact of MND.

The report states that the total cost of MND in Australia was \$2.37 billion in 2015, comprising \$430.9 million in economic costs and \$1.94 billion in burden of disease costs. These costs include \$32,728 per person related to the estimated 7.5 hours of care per day provided by family carers in addition to formal care.

The enormity of the cost is akin to the brutality of MND.

Assistive technology comprises one of the highest per person costs highlighting their importance. The often rapid rate of progression requires fast track access to a wide range and number of pieces of equipment as items may only be required for a short period of time, and multiple items may be required at any time.

For people living with MND the full range of assistive technology may include aids and equipment to support comfort, independence and daily living, communication technology and non-invasive ventilation to support breathing, quality and length of life. **Non Invasive ventilation (NIV) improves survival by 13 months on average².**

The report confirms the MND association equipment rental service as a cost effective model in providing assistive technology to maintain independence, safety and communication as needs arise and change.

In the NDIS roll out sites in NSW and Victoria people living with MND and planners are beginning to understand the cost effectiveness and benefits of including an up-front annual rental payment to the MND Associations as part of a person's support plan to enable fast track access to a 'bundle' of assistive technology provided by the Association.

² 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.



3. Submission

Scheme costs

Costs of business factors, such as quality, risk and profit have not been considered in the NDIS. These costs must be included if competition is to be encouraged and effective delivery of quality services and sustainability and innovation in service delivery achieved.

All the estimated 1000 people living with MND under the age of 65 are expected to be NDIS participants; however the range and level of reasonable and necessary supports needed vary greatly. Some of these people will be recently diagnosed and/or progressing relatively slowly and may not need to draw on supports immediately, whilst others will be very disabled or progressing rapidly and require a wide range of assistive technology, services and support.

Once people currently living with MND have entered the scheme we estimate that 300 to 400 people will be eligible to enter the scheme per annum. Each year the same number will likely die and therefore leave the scheme. The cost to the scheme related to people living with MND is therefore likely to remain fairly stable until an effective therapy is discovered.

The crucial issue is to recognise that MND is a rapidly progressive condition resulting in complex and changing needs which needs a rapid and responsive approach from diagnosis onwards. This means that planning must take account of the current and prospective needs created by MND. Given the focus on annual plans, planning for people with MND must include future needs.

In some cases, those future needs will not emerge, and so those funds may not be expended. Subsequent plans will adjust the estimated service needs and funding to reflect this progression. Funds not spent are then released back into the NDIA for allocation.

More people are entering the NDIA than predicted. This is due to many people not being clients of state funded disability services who have been surviving without supports. However, the availability of support from NDIA, as well as ageing of the population, has meant that those people come out of the woodwork, needing and looking for support. All people with MND who enter the scheme will leave the scheme.

MND Associations in NSW and Victoria have seen significant increases in registrations of people living with MND, and one reason for this has been the Association's participation in the NDIA and the prospect of accessing services and support that, in the past, were not going to be funded through State programs.

MND Victoria and MND NSW report registration of over 95% of the people with MND in their State.



The perceived financial and time constraints placed on LACs and Planners drives poor outcomes and poor plan utilisation. There is an apparent unwillingness to include adequate, or any, Coordination of Support. This means that a new participant, with no knowledge of services in their area (or acronyms) has no idea how or where to start implementing their plan.

From June 2016 until January 2017 100% of all Plans for people with MND in NSW and the ACT required review. The added cost to the NDIS, and the burden placed on the participants unable to access services, is considerable. This is due, primarily to a poor understanding of degenerative disease despite advocates attending most Planning sessions.

Inappropriate plans and an inefficient planning process have led to people living with rapidly progressive neurological conditions such as MND requiring plan reviews every time there is a change or deterioration in a person's condition. These reviews have been up to every 8 to 10 weeks for many people with MND. Plan reviews require the coordinators of supports to go through the whole process of getting reports from allied health and NDIA approval which is an extremely expensive and inefficient process.

Purchase rather than rental of Assistive Technology is a key driver of expense when considering rapidly progressive neurological disease. Access to assistive technology on a rental basis that can be provided rapidly is cost effective and essential. The Equipment Bundle provide by the MND Associations involves at up-front payment to enable access to a range of assistive technology available through their rental pool on an as needs basis during that 12 month period. Up-front payment enables the MND Associations to keep the annual fee as low as possible. This bundle may not meet all needs but is a cost effective starting point.

Scheme boundaries

Eligibility for the NDIS

All people with a diagnosis of MND who are under the age of 65 should be eligible for the NDIS. People with rapidly progressing conditions such as MND should be recognised as early entrants to the Scheme during this roll out phase to prevent crisis management, and therefore increased costs to the Scheme, and to minimize the danger of them falling through the gaps of service provision.

The exclusion of people aged over 65 has created significant disadvantage for people diagnosed with MND after the age of 65. As MND is not a disease of ageing, nor associated with the frailty in older people usually addressed by aged care planning and services, this exclusion has created discrimination for people based on age.

Aged care does not and cannot provide the same or even similar services to address the disabilities created by MND as the NDIS can and does. It is unfair and discriminatory that a person who is diagnosed with MND at age 64 is eligible for NDIS and will receive the services that are reasonable and necessary for their disability, while a person aged 66 can only access aged care, which is focused on



frailty and dementia, and does not understand disability and the needs it creates, nor the cost of services and support to assist someone to remain at home.

Further, NDIS does not require a contribution from the person, whereas Aged Care does.

The intersection with mainstream services

The complex and progressing nature of MND requires a coordinated interdisciplinary approach encompassing health (primary care, neurology, respiratory, gastroenterology, neuropsychology, nursing, palliative care and allied health), disability, community, aged, respite and carer support services. Seamless intersection between mainstream services and the NDIS is therefore imperative to ensure quality of life and cost effectiveness.

There is increasing concern regarding the impact of the free market on existing MND allied health teams who traditionally have worked together to provide a local coordinated approach to problem solve complex issues with people living with MND and their carer. In NSW Local Health Districts independently decided whether or not to become providers to the NDIS. To date most LHDs have decided not to be a provider which is proving disastrous for people transitioning between health and disability services with no continuity of care.

Planning processes

Funding available via ILC grants is insufficient – specialist organisations are best placed and should be funded to provide ILC type specialist supports to their constituents and to assist with pre-planning. The absence of support for the preplanning phase, which was previously funded by block grants in Victoria means that organisations do not have funding to invest in this crucial phase.

LAC's do not have the expertise to support people with MND.

In Victoria, the LAC is undertaking the first plans. They have no understanding of MND and the disability it creates. They attempt to plan via a telephone conversation, when speech and communication can be one of the early losses created by MND.

Due to their lack of understanding of MND and the disability it creates, we have plans that universally have to be referred back for replanning. This doubles the expense of the planning phase, distresses participants and support staff, creates an ongoing unfunded burden for services attempting to ensure that participants are properly supported by the NDIS. For example, planning done by LACs is limited to \$1,000 in value to purchase or rent assistive technology.

Further, because planning by LACs is done over the telephone, there is no review of the participant's environment. This can mean that issues such as accessibility, safety and appropriate assistive technology are not identified.

When a LAC planner does face to face planning, they often miss the obvious. Several people in Victoria had plans developed by the LAC planner that did not

include assistive devices – even though the participant was sitting in a wheelchair at the time! This is unacceptable. This error results in delays for service delivery and inconvenience and loss of support as the plan is submitted for review and correction. Face to Face meeting with NDIS planner with experience in complex neurological conditions is imperative.

For people living with MND, a relatively unusual cause of significant disability and death, planning should be undertaken by the specialist agency that has over 35 years of experience in working with and for people with MND – the MND Associations – with close monitoring and continuous auditing.

This would result in planning being quicker, more comprehensive, take into account the nature of the disease and the disabilities it creates, and take less time and therefore cost less. It would decrease the need for plan reviews saving the participant the trauma of waiting an extra 8-10 weeks for a plan to be implemented and dramatically reduce the costs to the NDIS.

Challenges related to planning to date (see Appendix):

- MND not included in the high priority group
 - State funded agencies are not taking on new people therefore a gap is created for people with MND who are not currently accessing services being unable to obtain services as the disease progresses
 - MND not being considered as complex for planning purposes
- Learnings of the trial being implemented inconsistently with no two jurisdictions the same in their approach to MND, or not being implemented at all
- Untrained information collectors and planners are resulting in the development of inappropriate plans
 - Offer of MND Association information and education has not been accepted or taken up. Expectation that the MND Associations will supply education and training for free because “you are charities”.
- A constantly changing landscape - in Victoria advice initially received was that people living with MND were considered Priority One and therefore plans would be undertaken by NDIA planner - three months in and LAC have now become involved. This has been the case in NSW since roll out began on 1 July
- Plans are taking too long to develop and approve, and taking too long to challenge and amend when errors are found
- Plans are based on the “now” and do not take account of the rapid and increasing needs caused by the progressive degenerative nature of MND, requiring review planning earlier than is necessary
- Coordination of Supports is not being included in plans despite the NDIA stating that **support coordination will benefit people with a conditions of a degenerative nature and supports require regular, active management and ongoing adjustments due to the participants changing needs**
- Lack of acknowledgement of benefits of expert advice – MND Associations have over 35 years of experience
- Unique needs of people living with MND is recognised by NDIA but not reflected or enacted in plans being provided
- LAC’s are disregarding individuals requests for Coordination of Supports

- LAC is irrelevant for people living with MND as they have complex needs and require a specialist planner to do plans
- NDIA is LAC and Planner focussed, and not focussed on the person with a disability and their needs
- At planning meetings assistive technology currently being hired from MND Associations is not being included in a person's plan as it is assumed that the assistive technology is owned by the participant. In some cases, despite sitting in a wheelchair, assistive technology is not included in the plan at all
- The requirement for NDIS participants to access plans via MyPlace is challenging and time consuming for people with a terminal condition, complicated for carers and family members, and not the way they wish to spend their last months and weeks of life
- Individuals who do not have coordination of supports included in their plans are having great difficulty understanding their plans, enacting plans and anticipating their future needs

Introduction of the Guidance Plan

We are hopeful the introduction of the **Guidance Plan for People with MND** will improve the planning process for people living with MND and the NDIA Planners. A process must be in place that ensures Planners in all jurisdictions are aware of this resource and encouraged and supported to use it. It is also vital that they understand the Plan is a baseline Plan which can then be individualized at follow up planning meetings.

The Guidance Plan will help to ensure that every person with MND has Coordination of support with sufficient hours included as well as a provision for assistive technology. The Plan gives people the option to include, at a minimum the MND Association Equipment Bundle in their plan so assistive technology can be requested quickly and delivered in a timely manner.

Specialist training for whoever is doing the planning is imperative. All LAC's and NDIA staff involved with people diagnosed with MND should undergo funded training provided by the MND association.

Existing services received:

Some people transitioning from state funded services to NDIS plan are finding that they are receiving fewer services via their NDIS plan. Respite care, required to ensure that family and unpaid carers do not break down under the strain, is excluded.

LAC's are not including existing services in plans, especially respite.

Market readiness

Will the workforce be ready? Will providers be ready?

Prices are not set at a level which is sustainable. Prices do not measure the true cost of delivery of services, and do not include funding for risk, quality, profit, research, innovation and infrastructure development. If there is an expectation that



organisations will enter and compete to deliver services in this market, the level of funding for services must reflect all costs and profit.

The alternative will be for services to be only delivered to participants that are low cost to provide and generate profits – cherry picking.

Will participants be ready?

MND clients should be participants from diagnosis. An alternative would be to fund MND Associations on a block basis to provide preliminary support and planning for every person diagnosed, based on an assessed number of hours of support.

It is vital that MND Associations are involved in the pre-planning process to support people with MND to be ready to become NDIS participants. Support from MND advisors and /or Coordinator of Supports is integral to assist people to negotiate plans and find and negotiate supports with providers.

Where appropriately supported, informed and accompanied to planning sessions, participants are ready to negotiate and develop plans. However, this is often frustrated by the lack of knowledge of planners about MND and the disabilities/progression inherent with the disease.

This could be rectified by the MND Associations being appointed as planners.

Governance and administration of the NDIS

There is too much focus on the number of plans written and not enough focus on the quality of planning. The transfer of planning responsibility to LACs has not driven output but has rather increased the number of plans requiring review. Similarly, financial reporting should not focus on the funds allocated, although that is an essential measure of the potential cost of the scheme, but also report on the funds spent, which needs greater emphasis.

Funds spent are less than funds allocated, as can be seen from the services utilised.



4. Conclusion

Implementation of the recommendations outlined in the Executive Summary of this submission will not only improve NDIS outcomes for people living with MND but will also directly improve outputs set out in the Productivity Commission's Services for people with disability performance indicator framework.

MND Australia remains an advocate of the NDIS and understands the roll out of this Scheme is one of the greatest changes to healthcare since the introduction of Medicare. However, if people with progressive neurological diseases such as MND are to receive equitable and effective support within the NDIS it is imperative that the NDIA and government address the issues highlighted in this submission.

MND Australia welcomes this inquiry and is available to provide further information if required.

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APPENDIX

Case Example 1 - Highlights that LAC's do not understand the impact of MND – specialist planning is vital for people with MND

- Female, housebound, no mobility, PEG, non-verbal, CALD family
- Currently receiving four hours of care per day
- Information gathering stage

Person's husband received call from LAC to advise information gathering session was to take place following week at the local LAC office (not in the person's home). Husband requested that a MND Advisor attend meeting.

MND Advisor questioned why the session did not take place in members home and was advised that the LAC could not do a home visit unless paid service provider present (there are support workers on-site 4hrs daily).

LAC asked why the member would not be attending the meeting in person. MND Advisor explained the nature of MND and the member's current condition. LAC had no knowledge of either. LAC then advised meeting could go ahead without the person with MND as there was no need for her to be present, evidence of disability already confirmed.

During the meeting the person's husband requested that Coordination of Supports be included in her plan. LAC responded that 'only those in group homes get Coordination of Supports' and that she could include the request but was 100% confident the Planner would deny same. LAC recommended this member request a Plan Management agency be appointed which would give them 'psuedo - Coordination of Supports' support.

Husband left meeting feeling very distressed and lacking confidence in the NDIS

Case Example 2 - Highlights need to involve MND Association in planning and to include Assistive Technology in plans from outset

- Female with impaired speech and complex communication needs
- Currently receiving support package
- Information gathering stage

Upon commencement of the NDIS roll-out an NDIA 'Information Gatherer' called the client. Unaware that this was a planning conversation, the client's husband, speaking on her behalf, gave an outline of current services in place however; he did not give a full picture to adequately inform a plan. Consequently, the client's first plan was approved without the assistive technology on hire from the MND Association being included and without being given the option to discuss her wish to have her MND Advisor included.

MND Association contacted the NDIA on behalf of the client and they advised that the client send a detailed email to the NDIA outlining the inadequacies of the plan.



Consequently, the NDIA immediately agreed to a plan review and MND Association was able to support the client to prepare properly for the next planning discussion.

MND Association also provided guidance and support to the planner to ensure the success of the plan review. While MND Association has not been given any hours for support coordination in the revised plan a new plan is now in place and it is far more appropriate in meeting the client's need. *(Our ability to confirm this is impeded, however, by the fact that the NDIA only provides the plan and a request for service to the nominated support coordinator who has not, to date, contacted the MND Association about the financial provision for hired equipment in the new plan)*

Case Example 3 - Highlights need for Coordination of Support to be included in plans from outset – minimum service NDIS Plan for people with MND entering the scheme which includes Coordination of Supports

- Male, advanced MND
- Currently receiving two person support services
- NDIA Managed with no Coordination of Support

Person received their Plan in the post and received a follow up call from LAC to advise that there is enough money in the budget to increase supports immediately. No further explanation of how to do this. Person's wife called MND Association to request provision of support coordination. MND Coordinator of Supports explained that could not do so in a formal capacity as there was no budget for this service included in their plan. Family became distraught as the wife had a health crisis and had no capacity to coordinate the necessary increase in services or assessments/assistive technology etc.

MND Coordinator of Supports began providing support to enact plan and request review from NDIA to resolve these issues ASAP. This included arranging urgent OT assessments and liaising with service providers – 4 hours provided so far none of which can be billed to NDIS. Review requested immediately via MND Association in an advocacy capacity

Case Example 4 - Highlights need for a LAC's to undergo training to ensure they understand MND and the need to include future needs in initial plan

- Male newly diagnosed
- Registered for MND Association services just prior to the NDIS roll out occurring in his region and linked in with MND Advisor.

MND Advisor was contacted by the LAC to gain an understanding of the role the MND Association play in supporting the client as he had advised them in his planning conversation that he wanted his MND Advisor included in his plan.

The MND Advisor explained to the LAC that the rapidly progressive nature of MND meant that while he may not need support coordination and assistive technology etc at this stage (i.e. now) this would change during the life of the plan.

It was also explained to the LAC that support and coordination needed to be included in his plan to enable him to continue to receive support from the MND Advisor and to enable the MND Advisor to provide input to future plan reviews.

The LAC did not understand why the MND Association would cease to provide services if not funded via an NDIS plan. The positive aspect of this call was that the LAC planner appeared to have a better understanding of the difficulty of forecasting the needs of participants with MND. She advised she would put some funding in his plan to allow the MND Association to provide support but not for support coordination.

Whilst understanding the need to develop open ended plans to allow client choice the MND Association is concerned that this client may not be able to interpret what funding he can use to engage appropriate services. His MND Advisor is arranging to meet with him to look through the plan, and confirm whether funding to enable him to seek support from an MND Advisor is actually included.

Case Example 5

Highlights need for existing services to be included in plans from outset– minimum service NDIS Plan for people with MND entering the scheme which includes Assistive Technology and respite should be introduced to minimise need for constant review

- Male with impaired speech, no mobility, non-invasive ventilation and complex care needs
- NDIA Managed, Coordination of Support included

Person received their plan that had no provisions for assistive technology other than repair and maintenance. The person had most of their existing assistive technology provided on hire from MND Association. Existing Saturday 6hr respite support was not reflected in plan

Review instigated immediately via Coordinator of Support

Case Example 6

Highlights that early access and MND Association involvement facilitates a streamlined approach to planning

- Male identified as an early entrant to the NDIS
- Active NDIS plan received nearly 2 years ahead of his scheduled roll out

Client's Social Worker contacted the MND Association to advise he had been identified by the NDIS for early entry. The MND Association was able to provide support and assistance through the process and was present, along with his social worker, at the face to face planning meeting.

His plan was approved with MND Association selected to provide support coordination and funding for assistive technology equipment on hire included. NDIA contact name and phone number given making a couple of administrative errors very simple to resolve.