

Response to Productivity Commission Position Paper

**NATIONAL DISABILITY INSURANCE SCHEME (NDIS)
COSTS**

Submitted online

By

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Executive Summary

Thank you for the opportunity to contribute to the Productivity Commission's National Disability Insurance Scheme (NDIS) Costs, Position Paper Overview and Recommendations. Our response to the draft findings, recommendations and information requests form this submission.

As outlined in our initial submission 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. MND Australia and member associations have been working tirelessly in the launch sites and roll out areas to support people with MND with pre-planning, planning, reviews and implementation of plans. Many of the findings in this Position Paper are supported by their experiences.

Key responses:

- MND Australia urges closer engagement with specialist disease specific organisations to develop an improved and more costs efficient planning process rather than a slowdown in the rollout
- Funding specialist disability/health organisations to undertake the LAC role for people with progressing and complex needs would be cost effective, timely and beneficial to all involved
- Phone planning is not effective and should not be used for people with complex and progressing conditions such as MND
- MND Advisors are best placed to alert people with MND and planners to the need for amendments or adjustments to plans as MND progresses without triggering a full plan review
- The inclusion of Coordination of Supports in a plan is essential when dealing with an acquired, complex, rapidly progressive and degenerative neurological condition such as MND¹
- MND Australia supports the intent of the ILC funding and agrees that increased and sustained investment is urgently needed.

If you have any questions, please contact Carol Birks, CEO, MND Australia

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



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:

- huge problems of adjustment for people who have MND;
- an escalating and stressful burden on carers and families
- 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
- the need for a coordinated response that addresses the person's disability
- 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, and facilitates ongoing community and family participation.

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.



Submission

Response to draft recommendations, findings and information requests

How is the scheme tracking?

DRAFT Finding 2.1

The scale and pace of the National Disability Insurance Scheme (NDIS) rollout to full scheme is highly ambitious. It risks the National Disability Insurance Agency (NDIA) not being able to implement the NDIS as intended and it poses risks to the financial sustainability of the scheme. The NDIA is cognisant of these risks.

MND Australia is cognisant of the scale and pace of the NDIS rollout to full scheme and the impact this is having on people entering the scheme and a wide range of stakeholders. MND Australia's members in NSW and Victoria have been closely involved in supporting people with MND from the introduction of the NDIS and have witnessed the impact of good planning vs poor planning. It appears that learnings from the initial sites with regards to planning processes that worked well for people with MND have not been translated to other sites. Each time a new jurisdiction comes on board the service provider's start from scratch in education and developing processes.

We believe that it is the process and design of the rollout that is increasing the risk that the NDIA will not be able to implement the scheme as intended rather than the scale and pace. MND Australia urges closer engagement with specialist disease specific organisations to develop improved and more cost efficient planning processes rather than a slowdown in the rollout.

Having a more consistent approach and translation of identified best practice across all jurisdictions would also help to ensure the integrity of the scheme and cost efficiencies.



Scheme eligibility

DRAFT Recommendation 3.1

When determining that an individual is eligible for individualised support through the National Disability Insurance Scheme under the disability requirements, the National Disability Insurance Agency should collect data on which of the activity domains outlined in section 24 of the National Disability Insurance Scheme Act 2013 (Cwlth) are relevant for each individual when they enter the scheme.

MND Australia has consistently advocated for the inclusion of people with rapidly progressing complex conditions such as MND to be eligible for the NDIS no matter their age. There are 2000 people with MND in Australia at any time. On average 50% are aged 65 or older when diagnosed. The aged care system remains focused on the frail age with little understanding of disability needs and we are facing increasing inequity for this relatively small group of people. Their inclusion in the scheme would be at a minimal cost to the scheme and could be funded by transfer of funds from the Aged Care budget.

Scheme supports

Information request 4.1

Is the National Disability Insurance Scheme Act 2013 (Cwlth) sufficiently clear about how or whether the 'reasonable and necessary' criterion should be applied? Is there sufficient clarity around how the section 34(1) criteria relate to the consideration of what is reasonable and necessary?

Is better legislative direction about what is reasonable and necessary required? If so, what improvements should be made? What would be the implications of these changes for the financial sustainability of the scheme?

As the scheme rolls out the reasonable and necessary criterion appears to be increasingly lost. The needs of the individual are subsumed by needs as interpreted by NDIA staff with little understanding of the person's condition. For example a person sitting in a wheelchair when their plan took place did not have assistive technology included in their plan.



Information request 4.2

Should the National Disability Insurance Agency have the ability to delegate plan approval functions to Local Area Coordinators? What are the costs, benefits and risks of doing so? How can these be managed?

To date LAC's have had little or no knowledge of disability, particularly rapidly progressive neurological conditions such as MND. Plan reviews have been necessary for most people with MND which is time consuming, costly and stressful for everyone involved. Anecdotally there is a high turnover of LACs and Planners who receive little training on disability let alone progressive neurological conditions. MND Associations have a well-established support service which includes MND Advisors who provide information, referral, education and support tailored to the individual and their family. All have a health or disability related professional background and are expert in MND. Funding specialist disability organisations to undertake the LAC role for people with progressing and complex needs would be cost effective and beneficial to all involved. Risks would be minimal.

The NDIA has consistently referred to conflicts of interest with respect to those involved in planning and service providers. Anecdotally, however, LAC's are able to include support connection in a person's plan and then provide that service.

As long as plans are being developed by LAC's with little knowledge of the impact of specific conditions the plan approval process should not be delegated to LAC's. If, however, plans for a person with MND were developed by an MND Advisor expert in MND then LAC's could take on the plan approval role.

MND Australia worked with the NDIA to develop the *NDIA Practice Guide for MND* which has been distributed to NDIA planners to assist them to understand the progressive and complex nature of MND. It is designed to highlight to planners the need to take into account the current and future needs of a person with a diagnosis of MND. The aim is to ensure that a person's initial plan contains sufficient supports for a person with MND until an individualized plan can be developed.



Unfortunately this guide appears to have fallen by the wayside and is not being used in the new rollout areas. In some instances when it is being used it is being used as a final plan and not being individualized as intended.

The inclusion of Coordination of Supports in a plan is essential when dealing with an acquired, complex, rapidly progressive disease such as MND. Assistance in unpacking a plan and locating service providers is daunting when there is no background or understanding of disability services. Increasingly Coordination of Supports is not being included which is of grave concern.

DRAFT Recommendation 4.1

The National Disability Insurance Agency should:

- *implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review*
- *review its protocols relating to how phone planning is used – phone planning*
- *provide clear, comprehensive and up-to-date information about how the planning process operates, what to expect during the planning process, and participants' rights and options*
- *ensure that Local Area Coordinators are on the ground six months before the scheme is rolled out in an area and are engaging in pre-planning with participants*

MND Australia congratulates the Productivity Commission on these recommendations.

For a person diagnosed with a rapidly progressing terminal condition such as MND wasting precious time on repeated plan reviews is not how they should be spending the last months or years of their life. Unfortunately most people with MND do not receive an initial plan that meets their current and/or future needs. The ideal would be for an individualized plan to be developed with specialist input from the outset that meets current and future needs (up to 12 months). As the disease progresses adjustments can be made without triggering a full review which is time consuming, costly and stressful. MND Advisors are well placed to alert people with MND and



planners to the need for amendments or adjustments to plans as MND progresses without triggering a full plan review.

Phone planning is not applicable for people with complex and progressing conditions such as MND as speech and communication may be impacted. In addition up to 60% of people with MND will experience some cognitive changes that may affect decision making.

Clear, comprehensive and up to date information about the planning process, to include rights and options, is vital.

MND Advisors are involved with people with MND as soon as they make contact with their MND Association. Most people have made contact with a MND Association within one month of being diagnosed. The Association's invest a lot of time in engaging in pre-planning and are therefore well placed to act as LAC's for people with MND and be funded appropriately. This would minimize duplication and ensure expert support for people with MND.

DRAFT Recommendation 4.2

The National Disability Insurance Agency should ensure that planners have a general understanding about different types of disability. For types of disability that require specialist knowledge (such as psychosocial disability), there should be specialised planning teams and/or more use of industry knowledge and expertise. –

In the launch sites in Victoria specialised progressive neurological planners were identified and in operation for some time which was working well. This highlights the issue outlined previously of a planning model that worked well not being translated to the rollout.

We support specialised planning teams for participants with progressive neurological conditions or for the MND Advisors to undertake this role. In either event people must be given the option of having their MND advisor present at planning meetings.

Boundaries and interfaces with the NDIS

DRAFT Finding 5.1

It is a false economy to have too few resources for Information Linkages and Capacity Building, particularly during the transition period when it is critical to have structures in place to ensure people with disability (both inside and outside the National Disability Insurance Scheme) are adequately connected with appropriate services.

DRAFT Recommendation 5.1

Funding for Information, Linkages and Capacity Building (ILC) should be increased to the full scheme amount (of \$131 million) for each year during the transition. The funds that are required beyond the amounts already allocated to ILC to reach \$131 million should be made available from the National Disability Insurance Agency's program delivery budget.

The effectiveness of the ILC program in improving outcomes for people with disability and its impact on the sustainability of the National Disability Insurance Scheme should be reviewed as part of the next COAG agreed five-yearly review of scheme costs. The ILC budget should be maintained at a minimum of \$131 million per annum until results from this review are available.

MND Australia supports the intent of the ILC funding and agrees that increased and sustained investment is urgently needed. ILC funding could be applied to support specialist disability specific agencies to undertake pre-planning and planning support. This would increase efficiency, reduce the need for plan reviews and save money in the longer term.

It should be noted that current access to ILC funds is difficult for smaller organisations that have limited resources to devote to writing grant applications.

Measuring the impact of the ILC program is vital

Provider readiness

DRAFT Finding 6.1

In a market-based model for disability supports, thin markets will persist for some groups, including some participants:

- *living in outer regional, remote and very remote areas*
- *with complex, specialised or high intensity needs, or very challenging behaviours*
- *from culturally and linguistically diverse backgrounds*
- *who are Aboriginal and Torres Strait Islander Australians*
- *who have an acute and immediate need (crisis care and accommodation).*

In the absence of effective government intervention, such market failure is likely to result in greater shortages, less competition and poorer participant outcomes

Information request 6.1

In what circumstances are measures such as:

- *cross-government collaboration*
- *leveraging established community organisations*
- *using hub and spoke (scaffolding) models*
- *relying on other mainstream providers*

appropriate to meet the needs of participants in thin markets? What effects do each have on scheme costs and participant outcomes? Are there barriers to adopting these approaches?

Under what conditions should block-funding or direct commissioning of disability supports (including under 'provider of last resort' arrangements) occur in thin markets, and how should these conditions be measured?

Are there any other measures to address thin markets?

People with conditions that are complex and progressing are likely to experience difficulty in accessing services to meet their needs particularly in regional, rural and remote communities. Leveraging existing specialist organisations, established community allied health teams, hub and spoke models of care and telehealth opportunities should be explored. A concerning consequence of the NDIS rollout is the loss of specialist allied health teams to the private sector, often concentrated in areas of higher density population. It may be cost effective to block fund well



established and experienced teams in thin markets. Cost of travel and time allocation for travel also needs to be considered and provided in regional, rural and remote areas.

Specialist organisations have an important role in educating and supporting new providers entering the market. This should be recognized and funded appropriately.

Workforce readiness

Information request 7.2

How has the introduction of the National Disability Insurance Scheme affected the supply and demand for respite services? Are there policy changes that should be made to allow for more effective provision of respite services, and how would these affect the net costs of the scheme and net costs to the community?

Flexible respite initiatives should be considered reasonable and necessary for the person with MND i.e a person with complex and progressing needs. While family members provide extensive ongoing support, there is no recognition that the provision of this support is dependent on the well-being and health of the carer. Respite for them is essential to help them maintain their well-being and health, and to continue providing significant uncosted and unfunded support for the person with MND. Often, when the carer breaks down, the only alternative is inpatient care in an acute hospital or aged care nursing home. This placement could be avoided in most cases through the provision of appropriate respite funding.

Participant readiness

Information request 8.1

Is support coordination being appropriately targeted to meet the aims for which it was designed?

Information request 8.2

Is there scope for Disability Support Organisations and private intermediaries to play a greater role in supporting participants? If so, how? How would their role compare to Local Area Coordinators and other support coordinators?

Are there any barriers to entry for intermediaries? Should intermediaries be able to provide supports when they also manage a participant's plan? Are there sufficient safeguards for the operation of intermediaries to protect participants?

Support coordination is vital for people with MND and should be included in a person's plan on entry to the scheme. Some MND associations are employing specialist staff to fulfil the role of Coordinator of Supports for people with MND. This role is very different to the MND Advisor role which focuses on pre-planning support, information provision, referral and service provider education. Where the roll out is slower other MND associations are widening the MND Advisor role to include coordination of supports.

Specialist organisations are well placed to play a greater role and, as specialists for a particular condition, have scope to be more effective and efficient.

Governance

Information request 9.1

The Commission is seeking feedback on the most effective way to operationalise slowing down the rollout of the National Disability Insurance Scheme in the event it is required. Possible options include:

- *prioritising potential participants with more urgent and complex needs*
- *delaying the transition in some areas*
- *an across-the-board slowdown in the rate that participants are added to the scheme.*

The Commission is also seeking feedback on the implications of slowing down the rollout.

As highlighted elsewhere in this submission MND Australia believes that issues with the NDIS rollout relate more to the process than the speed. Streamlining the planning process, engaging and funding existing specialist support organisations to take on LAC and planning roles will not only expedite the planning process, provide the relevant expertise but also dramatically decrease costs by reducing the need for plan reviews and decrease payroll pressure.

However, we would argue that people with progressive neurological conditions, like MND, should be prioritized. In particular, people with MND face rapid progression and death, and so require more intensive services and support for a shorter period.



DRAFT Recommendation 9.2

The Western Australian Government and Australian Government should put in place arrangements for Western Australia to transition to the National Disability Insurance Scheme. Any decision to join the national scheme should be made public as soon as possible.

The situation in WA remains complex and confusing for the MND community. MND Australia supports transitioning to the national scheme as soon as possible.



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