

**JOINT STANDING COMMITTEE ON THE NATIONAL
DISABILITY INSURANCE SCHEME**

**Inquiry into Independent Assessments under
the NDIS**

Submission from MND Australia

March 2021



MND Response on Proposed Independent Assessments

MND Australia and its members – six State MND Associations – have significant concerns with the planned changes to the NDIS including that independent assessments will be required as part of the access and eligibility process for prospective NDIS participants and will also be required as part of the plan review process.

We consider these proposed changes will be detrimental to those living with progressive neurological conditions such as motor neurone disease (MND). MND is a rapidly progressing, life limiting condition resulting in complex and changing disability needs which require a rapid and responsive approach from diagnosis onwards. Critically important is guaranteed access to the NDIS for those with a confirmed diagnosis of MND. Given that the condition is terminal, life expectancy short and deterioration inevitable, there is no question of suitability of access for people with MND.

And, expert assessment and planning is vital due to complex and rapid degradation of functional abilities and capacity. It is essential that assessment and planning are undertaken by people who have in-depth understanding of the person and the disease.

MND Australia considers that exemption from independent assessments for those with progressive conditions is essential. Without such exemption, MND Australia strongly believes that the necessary disease specific benefits of the NDIS, which have been developed progressively and collaboratively over the first years of the Scheme for people with MND, will be undone. Outcomes for people living with MND will be considerably poorer, lack the capacity for early intervention and may create significant risk of harm to the participants themselves and to their carers.

MND Australia strongly urges the Joint Standing Committee to intervene in the proposed change process and ensure the following:

1. people living with MND and other progressive, degenerative neurological and/or neuromuscular conditions who have potential to progress rapidly, based on the expert opinion of their specialist doctor, must be listed as exempt from undertaking an independent assessment in order to access the NDIS and require an assessment every time a person experiences functional decline and to support early intervention;
2. the new NDIA Functional Capacity Assessment Framework ensure that people living with progressive, degenerative neurological such as MND and/or neuromuscular conditions are assessed by specialists with knowledge and experience of working with people living with these conditions, using appropriate assessment tools;
3. the NDIA Functional Capacity Assessment Framework be amended to allow for the provision of functional capacity assessments and additional supporting information from members of an applicant's or participant's health care team;
4. the National Disability Insurance Agency (NDIA) postpone the implementation of the mandatory independent assessments until the second pilot is completed, outcomes determined and publicly released, with any revisions to the Policy considered and reflected in the design of the assessments process. If people living with a rapidly progressing disability have not been included in a pilot to date then we recommend a further pilot be conducted to include this cohort, and
5. that any required assessments are transparent, accountable and reviewable which allow participants to provide further information as required to ensure their needs are fully considered as part of the application process, or enable participants to appeal a decision in a timely way.

Background

About MND

Motor neurone disease (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. **The median survival is 2 to 5 years, although approximately 20 per cent of people may survive for 5 to 10 years^{1,2}.**

About 1 in 300 people will develop MND over their lifetime, with their risk of developing the disease steadily increasing as they get older³. There is no known cause for MND (except in 10 per cent of genetic cases), no effective treatments and no cure. Progression of MND is usually rapid and relentless creating high levels of disability and a consequent need for a wide range of supports based on the person's changing and progressing needs.

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 a significant challenge to the person diagnosed, their carer and family as well as the myriad providers involved in meeting the variable, progressing and complex care needs, particularly in regional, rural and remote communities.

Timely early intervention and access to expert multidisciplinary care, assistive technology, specialist planning, assessment and support coordination, including a proactive framework for decision-making, play vital roles in maintaining quality of life and independence. These interventions are also critical in helping people to plan ahead and prevent and/or delay 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 their caring role, health and wellbeing. Importantly, people with MND can and do live valued and engaged lives with the right supports, including assistive technologies and a multi-and inter -disciplinary approach, irrespective of disease stage or progression.

It is estimated that there are currently 2,000 people living with MND in Australia and around 50 per cent of these people were diagnosed when under the age of 65. All those living with MND under the age of 65 are eligible for the NDIS, however, the range and level of reasonable and necessary supports needed varies greatly. Some of these people will be recently diagnosed and may not need to draw on intensive supports for some months whilst others will be very disabled and require a wide range of assistive technology, services and support on entering the scheme. Approximately 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.

¹ Kiernan MC, Vucic S, Cheah BC, et al. Amyotrophic lateral sclerosis. *Lancet* 2011;377:942-955.

² Brown RH, Al-Chalabi A. Amyotrophic Lateral Sclerosis. *N Engl J Med* 2017;377:162-172.

³ Martin S, Al Khleifat A and Al-Chalabi A. [What causes amyotrophic lateral sclerosis?](#) [version 1; peer review: 3 approved]. *F1000Research* 2017, 6(F1000 Faculty Rev):371

Responding to Terms of Reference

a. The development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS

MND Australia is greatly concerned that the proposed introduction of the Independent Assessment Framework is being hastily implemented without fulsome consideration. There appears to be little openness to consultation feedback and little transparency, for example, the suitability of the organisations appointed to the Independent Assessment Panel to deliver “beyond one-size fits all” independent assessments from mid-year.

The introduction of independent assessments and the proposed planning policy will undo progress made for people living with motor neurone disease (MND) and lead to the need for lengthy and multiple assessment and planning process for people with progressing and changing disability needs. This would be an unnecessary and traumatic experience for people with life-limiting and often rapidly progressing conditions.

The introduction of independent assessments, in line with the other intended changes made available for public examination, will remove the vital flexibility and specialist planning developed and agreed with the NDIA for people living with MND and so significantly limit the scheme’s capacity to effectively support people living with MND. This appears to be a retrograde step to the collaboratively approach the NDIA has demonstrated over the past few years with MND Australia and the State MND Associations in developing disability/disease specific MND practice guide for planners (and an understanding that it was not appropriate for local area coordinators to undertake planning for people with MND), relationships and communication pathways to ensure people with MND receive timely and relevant plans and support (see recent case study).

A delay to the planned rollout of Independent Assessments Framework is required to allow transparent and fair consultation to be reflected in the design. MND Australia urges the NDIA to postpone the implementation of the independent assessments until the second pilot is completed, outcomes determined and publicly released, with any revisions to the policy considered and reflected in the design of the assessments process. If people living with a rapidly progressing disability have not been included in a pilot to date then we recommend a further pilot be conducted to include this cohort.

It is noted in the NDIA and Department of Social Services (DSS) joint submission to this Inquiry that ‘almost half of current NDIS participants have been required to source their own evidence of their functional capacity’. We consider this is inaccurate as it implies that all participants have to present functional assessments, and that almost half of all current participants have had to source, and so themselves pay for, that information. The reality is that not all participants are required to present that evidence. For those with MND, a neurologist letter confirming diagnosis is all that is required for NDIS access to be granted. No functional capacity assessment is needed. No additional evidence gathering is required as it is standard for such a diagnosis to be confirmed in writing to the person receiving the diagnosis.

b. The impact of similar policies in other jurisdictions and in the provision of other government services

MND Australia has no comment to make.

c. The human and financial resources needed to effectively implement independent assessments

The sustainability of the NDIS is a matter of importance for all. However, the introduction of independent assessments will not create cost savings for participants with MND. Functional assessments being undertaken by treating health professionals will continue to be required. The independent assessments will not replace any part of the current process and will instead add an additional, and frequently repeated, stage which will inevitably increase the NDIA's costs for people living with MND. Plans need to be developed by people who have in depth understanding of the person and the disease progression to avoid the need for an independent assessment each time there is functional change. Without this flexibility the NDIA will be wasting financial and human resources and also the limited time the person has left to live undertaking multiple assessments in order to access the support they need to live a meaningful life. In addition, without this flexibility, the current proposed minimum three-month rule between assessments will not meet the needs of people living with MND (see Appendix 1).

The effect of the independent assessments proposal, coupled with the changes the NDIS intends to make to the planning process, will be the creation of funding plans that require minimal human intervention beyond inputting data from the independent assessments to generate standardised funding allocation based on each functional impairment identified. This outsourced, automated approach perpetuates if not worsens the current 'one size fits all' capacity. People living with MND are already facing the inevitability of increasing functional decline, loss of independence and eventually loss of life. Wasting the precious time they have left being assessed for functional capacity that does not account for the rapid progression they will likely experience, is cruel and unnecessary.

Furthermore, in context of the Tune Review's key findings focused on independent assessments mitigating the need to provide further information about participants' functional capacity later in their NDIS journey so minimising the administrative and financial burden on participants. The reality for people with MND is that function will continue to decline and the proposed reliance on independent assessments to determine function will create an initial need, where the NDIA currently understands such assessment does not add value in determining necessary supports, and then require people with MND to undergo frequent re-assessment, again without adding value to the planning for what lies ahead. There is no current financial or administrative burden placed on people with MND due to the diagnosis itself being sufficient for access and therefore the introduction of independent assessments will have the opposite effect from Tune's intentions, for people living with MND.

d. The independence, qualifications, training, expertise and quality assurance of assessors

MND Australia has significant concerns with the capability of independent assessors to understand MND and its progression compared to a person's own treating health professionals.

As stated earlier, MND is a rapidly progressing, life limiting condition resulting in complex and changing disability needs which require a rapid and responsive approach from diagnosis onwards. Therefore, expert assessment and planning is vital due to complex and progressive decline in functional abilities. It is unequivocally essential that assessment and planning are undertaken by people who have in-depth understanding of the person, the disease and its progression.

Related to the foregoing, we are concerned that the current and emerging needs of a person living with MND cannot be determined in a three-hour observation session with an assessor. Often people in the early stages of their MND journey do not understand the disease nor predict their disease progression or how their functional decline may be impacted by their environment. This makes it extremely difficult and challenging for them to express their current and future needs with an independent assessor who has no or very limited knowledge and understanding of the disease and its progression. It is also critical that people living with MND trust the independent assessor/s to be understanding, knowledgeable and focused on having the best interests of the person living with MND at the fore of the assessment process.

The success to date of specialist organisations such as the MND Associations in providing training to the NDIS planners about the needs of people with MND must be recognised. This training will be difficult to conduct effectively with independent assessors working for multiple agencies.

e. The appropriateness of the assessment tools selected for use in independent assessments to determine plan funding

As previously stated, it is imperative that assessment and planning for people with MND are undertaken by specialists with knowledge and experience of working with people living with this condition. It is evident that the use of the assessment tools currently proposed will not be appropriate for those with progressing neurological conditions. Given the rapid change in functional ability experienced by people living with MND, tools that have been tested in this population and regular review are needed. Reviewing previous and present function, as proposed, will likely mean that key information related to the rapid progression and functional changes that will occur in the coming days, weeks and months with MND may not be identified early enough.

Furthermore, it is possible that some people will find the assessment process exhausting and unknowingly compromise the best outcome from the process. Fatigue is a common symptom of MND and an assessment process that will require considerable interaction for a sustained period of time will have a significant impact on an individual's wellbeing and this may well last for several days after the assessment. It has been suggested that the assessment can take place over a number of interactions. Whilst this may be beneficial from a fatigue reduction capacity, it will inevitably delay access to a plan and therefore vital funding.

As outlined in the submission from the MND NSW Special Interest Group, the current suite of proposed assessment tools will need to be extended in order to capture meaningful data across all domains for people with progressive neurological or neurodegenerative conditions. Further, this Special Interest Group that represents over 1,000 allied health professionals recommends that for people living with MND, specialised assessment of the environment should be undertaken by an expert health professional in collaboration with the individual. For example, an occupational therapist, in terms of physical environment and suitability with everyday activities, and speech therapist in terms of communication.

The NDIA and DSS's joint submission to this inquiry states that independent assessments are an 'essential tool to ensure equitable, transparent and consistent outcomes'. MND Australia fully supports equitable, transparent and consistent processes and tools. However, the reality is that independent assessments, as the only tool used, will not achieve that. Independent assessments are backward-looking and may well be used to give all prospective participants, who appear on a day with like functional capability, the same

starting point, with no understanding of what lies ahead for cohorts such as people living with MND. It seems that independent assessments will not take into account differences in circumstances of prospective participants which means that the achievement of equity and therefore fairness in outcomes is compromised.

The current system does not require all participants to provide a functional assessment to be granted access to the scheme. Exception is made for those participants in a cohort such as MND, where it is evident that today's functional assessment is not a sufficient indicator of the supports needed in the short term future. The proposed independent assessment process is, therefore, adding a stage in the process for many prospective participants in order to improve the access process for others.

f. The implications of independent assessments for access to and eligibility for the NDIS

Independent assessments should support fair and equitable access to and eligibility for the NDIS. However, it is likely that independent assessments will not achieve this. It seems counter-intuitive to the model MND Australia and its members have developed with the NDIA, one of partnership, collaboration and flexibility focused effectively on supporting people living with MND irrespective of where they are in the disease progression journey. For example, the NDIA recognizes the rapid, degradation of functional capacity in a person living with MND, during a plan period and encourages short (six month) plans in recognition of the unpredictability of the disease and the potential for rapid change. Even with this focus in the current system on increasing future needs, over 50 per cent of NDIS participants with MND generally require a 'change in circumstances' to be submitted for early review of their plan funding. Fortunately, the collaborative relationship that currently exists between the NDIA and MND Associations allows for access, planning and review processes to be expedited where urgency is flagged.

Additionally, early intervention is imperative to maintaining quality of life for people with MND and reducing the impact of the disease on informal carers. This will not be well understood by people at the beginning of their journey, nor will the independent assessment predict the need. A multidisciplinary care approach allows people with MND to live better for longer. Given that independent assessments will only be assessing need that is already evident, engaging a range of health professionals to undertake early necessary intervention in a coordinated way will not be an option for people with MND, if plans are set by independent assessment. As an example, one of the most critical early intervention activities relates to maintaining the capacity to communicate. Around 80 per cent of people with MND experience changes in their communication including the potential for loss of speech. The impact of this can be partially mitigated through proactive and pre-emptive measures to identify assistive and alternative communication methods such as voice or message banking but this will only be successful if it commences prior to any deteriorative changes in speech. A funding process that requires existence of functional limitations to precede funding will render this option obsolete effectively removing the possibility of maintaining the ability to communicate and therefore engage in the community and with family.

g. The implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports

In recognition of the complex and changing needs of people living with MND, most people with MND are now allocated to a planner, and in some areas to a specialist planner, with experience of progressive neurological conditions. These plans are now managed by NDIA planners (often senior planners), and not outsourced to Local Area Coordinators, due to the increased knowledge, experience and capability of NDIA staff. This MND specific planning

process follows the guidelines in the NDIA's MND practice guide, a document produced as a result of the collaboration between the NDIA and MND Associations.

The introduction of independent assessments appears to separate and minimise the role of planners. It is difficult to understand how plan development under the new NDIA Functional Capacity Assessment Framework will support the person to receive the reasonable and necessary supports to meet their goals as per the original premise of the NDIS.

Furthermore, the introduction of independent assessments has the potential to undo progress made and lead to the need for a multiple assessment process for people with progressing and changing disability needs. This would be an unnecessary and traumatic experience for people with life limiting and rapidly progressing conditions.

Plans need to be developed by people who have in depth understanding of the person and the disease, currently and during the disease progression to avoid the need for an independent assessment each time there is functional change. There needs to be flexibility noting that the current proposed minimum three-month rule between assessments will not meet the needs of people living with MND.

h. The circumstances in which a person may not be required to complete an independent assessment;

People with a disability that is complex and has potential to progress rapidly like MND should be exempt from undertaking an independent assessment in order to access the NDIS. Without such exemption, MND Australia strongly believes that the necessary disease specific benefits of the NDIS, which have been developed progressively and collaboratively over the first years of the Scheme for people with MND, will be undone. Outcomes for this cohort will be considerably poorer, lack the capacity for early intervention and create significant risk of harm to the participants themselves and to their carers and families. This is further emphasised for people who are newly diagnosed with MND and are unlikely to have the knowledge of the disease to understand how their functional decline can be affected by their environment.

It is noted the NDIA has not yet commenced rollout of independent assessments for children under the age of seven due to their potential to 'change rapidly'. Given that this potential exists equally for those with MND, the same consideration should be given for all of those with rapidly progressing neurological conditions.

It is also unclear how section 25 of the *National Disability Insurance Scheme Act 2013*, that includes people with neurological and degenerative condition as an early intervention group, will be reflected and supported within the Independent Assessment Framework. The aim of early intervention for this group of people is to strengthen the sustainability of informal supports available to the person, including through building the capacity of the person's carer. Undertaking an independent assessment that will only reflect the functional capacity of the person at that point in time will not support an early intervention approach and will instead lead to crisis intervention, avoidable hospital admissions and further stress and uncertainty for those with complex and progressing conditions, their carers and families.

i. Opportunities to review or challenge the outcomes of independent assessments;

MND Australia strongly believes that mechanisms should be in place to review or challenge the outcomes of independent assessments. This is even more important given the independent assessors are deemed to be independent of the NDIA.

Accountability, transparency and responsibility must stand strong in all decisions made that impact on the lives of people living with a disability, particularly for those living with a rapidly degenerative disease as MND. Any required assessments must be reviewable which allow participants to provide further information as required to ensure their needs are fully considered as part of the application process, or enable participants to appeal a decision in a timely way.

- j. the appropriateness of independent assessments for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds;**

The focus of the State MND Associations is on ‘care until there is a cure’ and the rollout of the NDIS has considerably advanced the care opportunities available to people diagnosed with MND under the age of 65, resulting in significant improvements in quality of life. However, as with all complex systems, the Scheme has its flaws, and in its original implementation was a “one size fits all” system, which led MND Australia and the State Associations to advocate for the unique needs of people with MND. The NDIA has recognised these unique needs, resulting in effective collaboration between the Associations and the NDIA, the implementation of MND specific processes in the current NDIS and hence to improved, and more appropriate, outcomes for this cohort than existed originally. MND Australia expects no less for people living with MND, whether or not the proposed independent assessments are implemented in their proposed or other form.

- k. the appropriateness of independent assessments for people with particular disability types, including psychosocial disability; and**

Please refer to previous responses.

- l. any other related matters**

Nothing further to add at this time.

RECENT CASE STUDY – NDIS access for person with MND

Contact received from wife (Sarah) of individual recently diagnosed with MND (James). Sarah advised that James is struggling with the diagnosis psychologically and had experienced significant functional decline in the last couple of weeks. As a result he was spending most of his time in bed.

James is still able to mobilise but experiences such significant fatigue that getting out of bed at all wipes him out for the rest of the day. James’ speech has declined to the point that he is very self-conscious in communicating with anyone although Sarah stated she is still able to understand what he is saying most of the time.

MND Qld provided support in completing the NDIS access request and Sarah finalised the form herself and submitted it on a Friday along with the Neurologist letter confirming diagnosis. MND Qld made contact with one of the Queensland’s NDIA directors on the following Monday and requested the access request be fast tracked given the urgency of support needs and quality of life concerns. Access was granted the following day and Sarah was contacted to schedule a planning meeting for the same week.

Had an Independent Assessment been required, these timeframes could not have been achieved, James would have been forced to engage with an unknown third party despite his self-consciousness about communication.

Additionally, the requirement to undergo a lengthy assessment would have exacerbated James' fatigue. It is likely that the assessment would have needed to take place in James and Sarah's bedroom which is a significant invasion of privacy in order to access the supports that he is clearly entitled to and desperately needs.

MND Australia thanks the joint standing committee for the opportunity to respond to its inquiry into independent assessments under the NDIS. We would be pleased to provide further information if required.

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APPENDIX 1

Independent Assessment case study example: John, 45 years old,

John is 45 and lives with his wife and two teenage children in Melbourne. He has noticed increasing weakness for over 12 months. He was finally diagnosed with motor neurone disease one month ago by a neurologist from the MND Clinic. He is experiencing fatigue and weakness in his left leg which is resulting in frequent falls. He made contact with MND Victoria who encouraged him to apply to the NDIS for support and provided information on how to make an NDIS access request.

John is using a wheelchair on loan from MND Victoria. His leg is becoming increasingly weaker and he has noticed changes to strength in his right leg. As the disease progresses he will need a customised power wheelchair to maintain his independence. He will also need paid disability support for personal care and some changes to his home so he can keep living there. John's wife would like to keep working and John would like to continue to work from home for as long as possible. John together with MND Victoria and his treating health professionals to complete an Access Request Form. This includes evidence of his age, residency and disability, including that his disability is permanent. The NDIA assesses John's application and find that he meets the initial access criteria. The NDIA asks John to complete an independent assessment and makes a referral to local independent assessor organisation.

John makes an appointment with his assessor organisation. This appointment will be at John's home. John is asked to show the assessor how he functions in his home, including how changes to his home will help him move around and continue working from home. John's wife attends the assessment and during the appointment, John and his wife will share information guided by the assessor's questions. The assessor focuses on how John has been functioning around the house but does not ask about how fast his condition is progressing or about how MND might impact his future needs. The assessor does not appear to know very much about MND and did not notice that John's speech became slurred towards the end of the assessment.

Following the independent assessment, the outcomes were provided to the NDIA to finalise a decision on John's eligibility for the NDIS. The independent assessment provides evidence that John's functional capacity is reduced. The NDIA determine that John meets the eligibility criteria and notifies John of the outcome of his request to access the NDIS shortly after his independent assessment. This also includes a summary of the independent assessment results for John's records. These results determine that John has leg weakness and is unable to walk. The assessment tools determined that his upper body function was normal and that he was independent using a wheelchair. John's independent assessment will now be used by the NDIA to develop his first NDIS plan.

John received his first NDIS plan three weeks later. By that time his right hand function had deteriorated and he is now unable to go to the toilet unaided. His speech is also beginning to deteriorate and he is anxious to start voice banking. Neither of these needs are reflected in his plan. John received funding in his plan for a customized wheelchair and rental of generic assistive technology from MND Victoria as needed. Flexible funds received to cover personal support, support coordination and allied health therapy are quickly expended as his MND continued to progress and his needs increased.

John waits three months for another independent assessment in order to adjust his plan and increase funds available. During this time he struggles to have his needs met and his wife is forced to leave work to care for him. He has a fall and is admitted to hospital.

Time taken in engaging with the NDIA and organising assessments impacts on time spent with his two teenage children and a longed for family holiday while he could still speak had to be postponed.